

**FACTORS INFLUENCING ADHERENCE TO HIV/AIDS TREATMENT AND  
PREVENTION AMONG PEOPLE LIVING WITH HIV/AIDS IN DAR-ES-SALAAM  
TANZANIA**

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There is a need to sustain African people living with HIV/AIDS (PLHAs) in good health for as long as possible, while at the same time preventing further risks of HIV transmission to self and others. Living with a HIV diagnosis creates what I have called HIV status stress. Using a HIV Status Stress Scale and an Adherence to HIV/AIDS Treatment and Prevention Scale that were developed for this investigation, along with two existing measures--the Sources of Social Support Scale and the Multidimensional Health Locus of Control Scale, this study sought to determine adherence to HIV/AIDS treatment and prevention among 212 participants randomly selected from two non-profit organizations in Dar-es-Salaam, Tanzania. Study findings highlight the direct effect of HIV status stress on decreased adherence to treatment and prevention regimes and on increased sexual risk behaviors. Informal social support was found to buffer the impact of HIV status stress on sexual risk. These findings hold important implications for public health and social work practice.

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## **1. CHAPTER ONE: INTRODUCTION**

In looking at the factors influencing adherence to HIV/AIDS treatment and prevention among people living with HIV/AIDS (PLHAs) in Dar-es-Salaam, Tanzania, we must first look at the history of HIV/AIDS in Africa, starting with examination of the literature (Ankrah, Schwartz, & Miller, 1996; Hope, 1995; Killewo, 1994; Mann, Tarantola, & Netter, 1992). In 1982, only one African country, Uganda, had an estimated HIV prevalence rate higher than two percent (Ankrah, 1993; Museveni, 1991). However, by the early 1990s, some were beginning to fear for the future of Africa (and Uganda in particular), as they compared AIDS to the Black Death of 1347-1351 (Barry, 2004), which killed one third of the population in Europe (Henderson, 1993). In Uganda at the time, AIDS had become the number one cause of adult mortality (Achieng, 1999; Ainsworth & Semali, 2000; Henderson, 1993; Hunter & Williamson, 2000; Over & Huq, 1991).

Over 40 million people worldwide are thought to be infected with HIV, with over 30 million of these people residing in Africa (UNAIDS at Barcelona, 2002). Some critics say that the impact of AIDS in Africa has been exaggerated, alleging that the reported high rates of HIV prevalence are due to poor record-keeping in sub-Saharan Africa (Donnelly, 2003). A report by Donnelly (2003), however, estimated that between 34 million and 46 million were infected worldwide. This conclusion was based on data collected from pregnant women at pre-natal clinics and from door-to-door surveys in at least seven countries.

No matter how one looks at it, Africa is the continent hardest hit by HIV/AIDS (Calvarese, 2001; Henderson, 1996; Sabatier, 1989). It is a continent that accounts for more than two thirds of all HIV/AIDS cases in the world, although it comprises only ten percent of the entire global population (Akukwe & Foote, 2001).

As for Tanzania, ded (Deutscher Entwicklungsdienst), a German development agency, estimated that in 1999 one and a half million Tanzanians were living with HIV/AIDS (ded, 2001), which represented an infection rate of about 20% (NACP, 2001). Other sources have said that close to 2 million Tanzanians are living with the HIV virus (Agence France-Presse, 2001). This, according to the National AIDS Control Program (NACP), represented an infection rate of over 20% (NACP, 2001). The rate of infection in a major city like Dar-es-Salaam has been even higher. A recent report indicated that from July 1998 to June 1999 AIDS and TB ranked as the number one causes of death for both men and women aged 15-59 years (NACP, 2002). Dar-es-Salaam has reported higher rates of HIV infection than any other part of the country, with an infection rate of 10-20% (NACP, 2000, 2001).

Notwithstanding the high rates of infection, Africa has been able to keep going mainly because people in the communities that have been hit hardest by HIV/AIDS have relied on each other for support to sustain their morale in their battle against the AIDS epidemic (Setel, Lewis, & Lyons, 1999). Given that people may live happier and healthier lives when they have access to rich, rewarding, and supportive social relationships (Cvitanic, 1993; Linn, Monnig, Cain, & Usuh, 1993; Taylor, Falke, Maze, & Hilberg, 1988), empirical research is needed to provide data on how social support applies to the African experience of HIV/AIDS. In particular, investigations are needed

of the factors influencing adherence to treatment and prevention strategies available in the African context, and the possible buffering role of social support in these relationships.

### **1.1. HIV/AIDS in Tanzania**

According to Nguma (1992), the history of AIDS begins in northwestern Tanzania, where AIDS first took its toll on young men and women involved in illegal trade with Zaire, Rwanda, and Burundi. Here the trade flourished on illegal buying and selling of currency, minerals, alcohol, and basic commodities that were in short supply in Tanzania, especially after the war with Uganda in the late 1970s (Nguma, 1992). People began to die in great numbers and symptoms were so mysteriously similar that witchcraft was the only explanation that the community could offer: “they believed that witchcraft was the main cause of these deaths and that those dying were bewitched” (Mann, Tarantola, & Netter, 1992, p. 332).

The first two documented cases of AIDS in East Africa were identified in 1981 in Rakai, a southern Uganda district that borders the Kagera region of Tanzania (Bertozzi, Ankrah, Koda & Ngaiza, 1990; Kalibala, Rubalamira, & Kaleeba, 1997; Killewo, 1994; Museveni, 1991). In Tanzania, the first three cases were identified in 1983 in the Kagera region (Ainsworth & Rwegarulira, 1991; Kaijage, 1993; Killewo, Gregorich, Sangiwa & Coates, 1998; Laing & Pallangyo, 1990; Lwihura, 1988; Mann, Tarantola, & Netter, 1992; NACP, 1989; Nguma, 1992).

With a population of nearly 36 million, Tanzania presently has an estimated average of between 1.3 million (CDC, 2002) and 2 million (Agence France-Presse, 2001) HIV infected people, and more than 1.1 million children who have lost one or both

parents due to AIDS. Current HIV/AIDS estimates, however, may underestimate the scope of the actual situation. Goergen (2001) cites a study in Morogoro (the region closest to Dar-es-Salaam) that showed that only 10% of women and 18% of men who died of HIV/AIDS were in a hospital at the time of their death. All the others died in the community, where death statistics are rarely reported. Goergen's (2001) study also pointed out that Dar-es-Salaam has reported the country's highest infection rate [32% in women (antenatal studies) and 13% in men (blood donors)], while Kigoma in the west (the region east of Lake Tanganyika) has the lowest rate (3% in women and 4% in men)

Unlike other countries where researchers typically find a single predominant subtype of HIV-1, Tanzania has the widest range of HIV subtypes found in Africa (Renjifo, Mwakagile, & Kapinga, 2003). According to the Chair of the Harvard AIDS Institute, Tanzania is the one place in the world that displays a fairly high rate of infection as well as a landscape of different viruses (Essex, 1999).

#### **1.1.1. AIDS Service Organizations**

Across Africa, the 1980s marked the beginning of a mushrooming of support groups and AIDS service organizations (ASO), non-governmental organizations (NGO), and community based organizations (CBO) involved in AIDS care advocacy. The Ugandan AIDS Support Organization (TASO), the Salvation Army AIDS Project in Zambia (Chikankata), and WAMATA (Walio katika Mapambano na AIDS Tanzania, meaning "people in the frontline against AIDS in Tanzania") began to make an impact on the care and support of AIDS affected families and PLHAs (Family Health International [FHI]/USAID, 2002).

These groups also began to form linkages with similar organizations in other countries. The London Lighthouse, the International Coalition of AIDS Services

Organizations (ICASO), and the AIDS Coalition to Unleash Power (ACTUP), were some of the partners that influenced the work of the African organizations (Elbazar, 1992; Gould, 2000; Hartwig, 2001; Mann, Tarantola, & Netter, 1992).

Locally, too, they began to influence change. Since the late 1980s and early 1990s a number of CBOs, ASOs, NGOs, faith-based organizations (FBOs), and other non-profit organizations have been involved in giving care to PLHAs. According to a joint report by FHI and USAID, some of the pioneering AIDS care programs include those by WAMATA and PASADA in Dar-es-Salaam, the Anglican Church in Dodoma, and both the Evangelical Lutheran Church (ELCT) and the Catholic Church in Kagera and Arusha (USAID, 2002). SHDEPHA (Service Health and Development for People Living Positively with HIV/AIDS) was started in Dar-es-Salaam in the early 1990s.

At present, all of the East and Central African countries have been affected by HIV/AIDS (Astatke, 2001; Damesyn, 2002; Karanja, 2002; Lay, 2001; Porter, 2002; Quinn, 2002; Salomon & Murray, 2001). Like elsewhere in sub-Saharan Africa, every family in East Africa has lost someone either in kinship relations, at work, or in the neighborhood, where funerals are held each day. Although the myths about AIDS being caused by witchcraft did not help in controlling the spread of HIV infection, neither did they obstruct care. Unlike the biomedical explanations, witchcraft beliefs did not induce the fear of contagion that has led to the stigmatization of AIDS patients. Witchcraft is believed to affect only the person to whom it is directed or intended (Mesaki, 1993), whereas a contagious disease can affect all with whom the infected person has contact.

With knowledge that AIDS was an incurable, sexually transmitted disease, families slowly began retreating from the tradition of caring for their members who had

been diagnosed with AIDS. As some authors on AIDS in Africa have suggested, compassion needed to be restored in the African family, which historically had maintained a tradition of supporting its most vulnerable members (Ankrah, 1993; Kaijage, 1993; Killewo, 1994; Thindwa, 2002).

In 1985 the government had established the Tanzania AIDS Task Force, which trained health workers about the clinical manifestations of AIDS and introduced the concept of counseling. In 1987, the Task Force was replaced by the National AIDS Control Programme (NACP), which is a section under the infectious diseases directorate of the Ministry of Health, as required by the first national Medium Term Plan (MTP1), 1987-1991 (NACP, 1992).

Nevertheless, there are limits to what can be achieved with meager resources such as those available in Tanzania. With an external debt of \$8.3 billion and an overall per capita health expenditure of less than \$4.00, the overall program budget for HIV/AIDS was only \$35,465,752 for the period 1992-94. Of that amount, only \$7,465,196 was made available to NACP (Harvard School of Public Health, 2003). By the early 1990s, WAMATA and other ASOs had begun to provide alternative care for AIDS patients at home. Hence, the value of family was restored and home care encouraged. Meanwhile, there was an increase in lay participation in voluntary HIV/AIDS activities. There was also an increase in funding to hire ASO staff for HIV testing and counseling programs.

All this helped to bring about positive changes. African community response to HIV/AIDS slowly emerged (NACP, 1989; Sabatier, Foreman, Tinker & Radlett, 1989; Sangiwa, van der Stratten, & Grinstead, 2000). With antiretroviral therapy helping the PLHAs who have access to it live longer (Andersen, 1999; Bentz et al., 2002; Chesney,



Ickovics, Hecht, Sikipa, & Rabkin, 1999), there is a need for behavioral interventions to promote health and prevent further HIV transmission (Cvitanic, 1993; Dayton, & Merson, 2000), not only in the West, but in Africa as well. It is important, therefore, to begin to combine all efforts to sustain African PLHAs in good health for as long as possible, while at the same time preventing further risks of HIV transmission to self and others (Henderson, 1996; HIVdent, 2001).

The Tanzania programs by the AIDS Commission (TACAIDS), the NACP of the Ministry of Health, professional associations, and a variety of non-governmental, ASOs, and private organizations have played a big role in mobilizing the public to access available treatment and also to prevent further spread of HIV/AIDS (NACP, 2001; TACAIDS, 2002, TAMWA, 1997). The major mobilization tool has been the media, especially the radio. Unlike television, which serves only the affluent, urban-based population, one radio can serve a whole rural Tanzania neighborhood, and unlike newspapers, which require literacy, people who cannot read or write enjoy listening to radio in Tanzania (UNESCO, 2000).

## **1.2. Theoretical Background to the Problem**

The stress of living with HIV/AIDS, which in this study is referred to as HIV status stress (HSS), features in the literature as an issue deserving further research (Daniels, 2001; Dayton, & Merson, 2000; Dickey, Dew, Becker, & Kingsley, 1999). Living with HIV status stress starts at the infection stage, when the virus that causes AIDS enters one's body (Benedict, 1996; Demas, 2002). Infection is often followed by an acute reaction that then resolves itself into a long period of incubation when the infected individual does not feel or show any symptoms. At some point the individual begins to

show symptoms that eventually lead to a diagnosis of AIDS, which in the absence of pharmacological interventions causes death (Beaudoin, 1992; Benedict, 1996; Berger, 1998).

The whole period of living with an HIV diagnosis is dominated by stress (Benedict, 1996; D'Cruz, 2002; Dilley et al., 1985; Rigby, 1995). It is not hard to understand why stress may be a dominant feature of living with HIV/AIDS, and studies of HIV-related stress and stigma illustrate how these factors impact the lives of PLHAs (Berger, 1998; Ness, 1999, Nyblade et al., 2003). A study conducted in Ethiopia, Tanzania, and Zambia has shown that the people most likely to experience “HIV-related stigma commonly have the fewest resources to cope with and resist it” (Nyblade et al., 2003, p. 9).

In Africa, the period of living with the knowledge of an HIV diagnosis may be short, even if intense, because many PLHAs are diagnosed after developing the symptoms (Damesyn, 2002; Kalibala, Rubalamira, & Kaleeba, 1997; WAMATA, 2001), but the impact of HIV stress goes on even after the person dies (Brown, 2000; Donahue, 1998; Kubler-Ross, 1969; Michiels, 2001). The World Bank (1992) noted that in Tanzania, death occurred within a year or two of the onset of major AIDS symptoms, and recommended that AIDS patients be cared for at home as hospital care is too costly (The World Bank, 1992).

Due to limited options for treatment and care, the Tanzanian PLHAs die sooner than their counterparts in the developed world where there are more treatment options (Donnelly, 2003; Essex, 1999; Henderson, 2000; Webb, 1997). That means African PLHAs have less time to prepare their loved ones for their death, and this is yet another

source of their stress (Donahue, 1998; Draving, 1996). For the family of the individual PLHA, then, stress continues throughout the stages of mourning after that individual has died of AIDS (Burkhalter, 1997; Coleman, 1996; Gluhoski, Fishman, & St Perry, 1997; Haslwimmer, 1996; HIVdent, 2001).

Although the utility of social support applies to all people in all situations (Diver, 2002; Lubana, 1999; Vaux, 1988; Vaux, & Harrison, 1985), this study sought to assess the function of social support for Tanzanian PLHAs who have limited options for treatment (Bazira, 1994). Social support may play a crucial role in helping individuals manage stress (Gluhoski, Fishman, & St Perry, 1997). It also may foster PLHAs' sense of control and stimulate their desire to live positively by adhering to the HIV/AIDS treatment regimens, while also preventing the spread of HIV/AIDS (CDC, 2000; Chesney, & Folkman, 1999; Coates, 1990; Dayton, & Merson, 2000; De Rosa, & Marks, 1998).

Theories of health locus of control suggest that people attribute control and responsibility for their own health to either internal or external sources. Health locus of control is known to impact health conditions (Phares, 1976; Wallston, Stein, & Smith, 1993), this study was based on the premise that health locus of control also impacts adherence to HIV/AIDS treatment and prevention.

### **1.3. The Current Study**

The research on Africans living with HIV/AIDS is minimal compared to what is known about PLHAs in Europe and the US where PLHAs have participated in biomedical and social science research for decades (Salomon & Murray, 2001). In Africa, where whole communities and nations have been affected by HIV/AIDS, the AIDS

epidemic is a complex problem (UNAIDS, 2001). This study addressed this complexity from the perspectives of social work and public health research.

The focus of the study was on: (1) the impact of HIV status stress on PLHA's adherence to HIV/AIDS treatment and prevention; (2) the role of health locus of control as a mediator in the relationship of HIV status stress to adherence to HIV/AIDS treatment and prevention; (3) the role of social support as a moderator, or buffer, in the relationship of HIV status stress to adherence to HIV/AIDS treatment and prevention; and (4) the role of health locus of control as a mediator in the relationship of social support to adherence to HIV/AIDS treatment and prevention. To explore these issues, the study used a cross-sectional survey design and involved in-person interviews with PHLAs who were clients of two ASOs in Dar-es-Salaam.

### **1.3.1. Significance of the Current Study**

This study of the factors influencing adherence to HIV/AIDS treatment and prevention among Tanzanians living with HIV/AIDS in Dar-es-Salaam both explored and explained what may help to sustain Tanzanian PLHAs in good health, while at the same time reducing further risks of primary and secondary HIV infection. Since every new infection begins with someone who is already infected, it is a missed opportunity if PLHAs have access to AIDS treatment and care without combining treatment with access to services for the prevention of HIV transmission (Akukwe, & Foote, 2001; Andersen, 1999; Beeker, & Guenther-Gray, & Raj, 1998; Benedict, 1996; Calvarese, 2001; NACP, 2001). The study has implications for the public health approach to the prevention of disease. It directly targets the population affected by HIV/AIDS to solicit information that can be useful in improving the care of both infected and affected populations.

The study also has significance for Tanzanian social workers and policy makers. Findings can be used by these audiences to design intervention programs aimed at sustaining PLHAs in good health and at supporting them in their adherence to HIV/AIDS treatment and prevention. Study results also can enable social work practitioners to educate Tanzanian PLHAs and their families on how to cope with HIV status stress in ways that promote better adherence to HIV/AIDS treatment and prevention. More importantly, the research process and study results potentially helped Tanzanian PLHAs feel empowered enough to take advantage of the social support networks that were available to them to overcome their stress and to enhance their adherence to HIV/AIDS treatment and prevention. Overcoming stress associated with their HIV status may lead to further empowerment. Hence, the PLHAs may subsequently feel that they can improve their general well-being as well as their quality of life. Thus, they may be able to live longer and healthier lives, while at the same time preventing further HIV transmission to self and others.

## 2. CHAPTER TWO: TANZANIA PAST AND PRESENT

Tanzania, which lies on the Eastern African coastline (Indian Ocean), is more than twice the size of California and is the largest of the three East African countries (i.e., Tanzania, Kenya, and Uganda). Its land area is 945,090 sq km (364,879 sq mi) but, of that, only 881,300 sq. km is dry land. Tanzania's population approximates 36 million people who are ethnically and linguistically diverse (Baker, 1947; Schmidt, 1997), but united through one common language, Kiswahili (Tanzania People, 2000).



**Figure 1 Map of Tanzania**

Only 30% of the Tanzanian population resides in urban areas (Campbell, Mwami & Ntukula, 1995). The city of Dar-es-Salaam is the country's major urban center (Campbell, Mwami & Ntukula, 1995; Mhamba & Colman, 1999; Ngware & Kironde, 2000). Tanzania is a developing country that has a traditional rural agriculture sector (Beegle, 1997; Sosovele, 2002; Tibaijuka, 1988), and a small, or weak, urban-based

commercial sector (Bates, 1987; Rutashobya, 1995; Tripp, 1989). Agriculture accounts for 50-60% of the gross domestic product (GDP) and about two-thirds of exports (Tax, 2000). The official currency is the Shilling (TSh.), which is divided into 100 Cents; one US dollar is equivalent to 100 Tanzania shillings (TSh.).

As one of the world's least developed countries (UN, 2001), Tanzania's annual per capita income is US \$200 (Agence France-Presse News, 2000). The country has had its years of plentiful harvest, especially during the 1960's when it had the highest rate of increase in domestic food production in Africa (Lofchie, 1989). This compensated for the low per capita income because the country did not have to import food. Nevertheless, in the 1970s and 1980s Tanzania experienced the worst food shortages in its history and it changed from being a food-exporting country to a food-importing country. Yet, as Sarris and van den Brink (1993) reported:

Despite the fact that Tanzania is one of the world's poorest countries (the fourth-poorest, according to the 1990 World Bank Development Report), it has managed to weather all storms with a remarkable degree of political stability, and without extreme hardships such as the famines that hit other, more-developed countries. (p.1)

The socio-economic and political context of HIV/AIDS in Tanzania may not be different from that of other African countries, but Tanzania was at a crossroads when the AIDS epidemic entered its borders. It had fought and won a war against the former President of Uganda, Id Amin, in 1978-1979. However, by doing so, it had lost its place in the world as a country that had managed to use nonviolent means to resolve conflicts, having won its independence in 1961 by arguing a constitutional case, rather than by shedding blood (Kimambo & Temu, 1969; Legum & Mmari, 1995).

Moreover, it was the very northwestern border that had been contested in the war with Uganda that became the first battleground in a new and different kind of war against a new kind of invader, the AIDS epidemic. It is important, therefore, to start this chapter by examining the historical development of Tanzania, which was created as a nation by the merger of two countries--Tanganyika and Zanzibar-- so as to highlight some things that distinguish the country and its people from its neighbors. It is this history that has influenced how the people and government of Tanzania have responded to HIV/AIDS.

## **2.1. A Brief History of Tanzania**

### **2.1.1. The Pre-Colonial Period**

Oldvai Gorge has distinguished Tanzania as the cradle of humankind (Leakey, L.S.B, 1951; Leakey, M.D., 1994), and its civilization goes back to pre-historic times (Katoke, 1971; Mgomezulu, 1981; Schmidt, 1997), but most of that is not written. Until the advent of modern education, history was lived, not written, and that lived experience was documented in oral traditions and customs that shaped the culture and that were passed from one generation to another through socialization (Glave, 1897; Whiteley, 1959).

Some of that history tells us that as early as the beginning of the 8<sup>th</sup> century, Arab traders started to arrive and settle among the Africans who lived along the East African Coast (Amiji, 1983; Elton, 1874; Pouwels, 1974; Sykes, 1853; *The Story of Africa*, 2003). By the 12th century, traders and immigrants came from as far away as Persia (now Iran) and India and began to build a series of highly developed cities and trading states along the coast (Baxter, 1944; Mamdani, 1969; Tanner, 1952). Kibaha, which is now the capital of the coastal region that surrounds the city of Dar-es-Salaam, was one such city. It was mainly settled by the Persians (Amiji, 1983; Gray, 1962).



The foreign traders, who settled at the coast, and their indigenous East African hosts mutually exchanged goods and services as equal partners who respected each other's boundaries of civilization. Resulting from this mixture of cultures (i.e. Arab traders and Coastal Africans) was the emergence of a people and culture known as **Swahili** (Allen, 1974; Mazrui, 1992; Reusch, 1953). It was not until the 18<sup>th</sup> century that the relationship between Africans and Arabs turned into that of slave and master (Alpers, 1967; Austen, 1988; Clarence-Smith, 1988; Pierson, 1992; Robinson, 1939; The Story of Africa, 2003).

## **2.2. The Arrival of the Europeans and the Advent of Colonialism**

European interest in the Tanganyika was sparked by its fascinating geography (the three biggest lakes in Africa [i.e. Lake Victoria, Lake Tanganyika, Lake Nyasa or Malawi], the highest snow-capped mountain in Africa [i.e. Mt. Kilimanjaro], the African Rift Valley, the Serengeti National Park, and the Ngorongoro Crater); its strategic location on the Indian Ocean; its association with the Olduvai Gorge, which is believed to be home to evidence of the earliest human ancestors; and its other natural resources and treasures (i.e. minerals, animal skins, and tusks) (Deasy, Furzer, Jackson, Turnball, Walker, & Yeo, 2001). It was inevitable, therefore, that this vast equatorial land should have been subject to European settlement and years of colonial rule (Cory, 1956; Illife, 1969, Rosenber, 1999).

**2.2.1. Portuguese East Africa.** The Portuguese arrived towards the end of the first half of the 15<sup>th</sup> century. It was the Portuguese fascination with traveling to India that brought this region of Africa to their attention. To make their voyage to India, the Portuguese sailed south via the West African Coast, around the South African Cape, then

up the East African Coast before heading off to their destination. The East African Coast, thus, represented a strategic area necessary for ensuring Portuguese commercial and maritime dominance of the Indian Ocean (Gray, 1961).

By 1506 the Portuguese had succeeded in controlling the East African coastline, stretching between Kenya and Tanzania (including Zanzibar) to the north and Mozambique to the south (BBC Timeline, 2001). Hence, this East African coast was known as Portuguese East Africa (Gray, 1961). The Portuguese were ousted from Zanzibar in 1699 by the Omani Arabs, who went on to rule Zanzibar until its independence in 1963; by 1729 they were driven out of the rest of the East African coastal region (BBC Timeline, 2001). Portuguese rule was, thus, confined to Mozambique until 1980, when they gave up their only remaining colony and granted it its independence.

Both before and during the period of Portuguese control, trade in the region involved not just local materials, such as ivory, but also the capture and exchange of people. The slave trade grew more organized during the early 1700s and pushed ever farther inland. The slave trade route eventually cut through the heart of Tanzania from the inland great lakes region that surrounds Lake Victoria and Lake Tanganyika to the shores of the Indian Ocean. Long caravans of slaves captured by Arab traders came from as far inland as the central African country of the Congo to Bagamoyo on the eastern shores of the Indian Ocean. From there, many slaves were sent to the offshore island of Zanzibar to be exported to the Middle East (Abir, 1968; Beachey, 1976; CPHRC, 1998; Mpangala, 1992; Salim, 1984). The survivors of the slave trade era ended up settling in Bagamoyo, Zanzibar, and elsewhere along the coast and the central line that had been the slave route.

**2.2.2. German East Africa.** After the Portuguese lost control of the East African coastal region in the early 1700s, the Arabs maintained control of the region. However, in 1884, Karl Peters, a German merchant, arrived and befriended the indigenous people; their chiefs eventually offered him land, assuming that he was like other traders who needed land to settle (Osborne, 1960). Unlike those before him, however, Karl Peters was an agent for Society for German Colonization and was backed by his government. He had come to East Africa with the intention of establishing the German East Africa Company (Illife, 1969; Sunseri, 1993; Wright, 1971).

In 1884-1885 the Berlin Conference set the ground rules for what has come to be known as the Scramble for Africa (Porter, 1991; Rosenber, 1999), and the territory known as Tanganyika fell within the German sphere (de Blij & Muller, 1999; Notholt, 1996; Rosenberg, 1999; Sheriff, 1987). By 1890, German East Africa included the territories of Tanganyika, Burundi and Rwanda (Morley, 1996). As de Blij and Muller (1999) observed, the Berlin Conference was Africa's undoing in more ways than one.

The colonial powers superimposed their domains on the African continent. By the time independence returned to Africa in 1950, the realm had acquired a legacy of political fragmentation that could neither be eliminated nor made to operate satisfactorily (de Blij & Muller, 1999, p.340).

As soon as Tanganyika came under their control, the Germans embarked on some development projects to facilitate their control of the country. In 1891, the colony's first railway was built inland from the eastern port of Tanga, north of Dar-es-Salaam (Illife, 1969). This facilitated the expansion of European agriculture, which, according to Illife (1969), accompanied the railway inland and reached as far as the eastern part of the Usambara Mountains in the early 1890s (McCarthy, 1918). By the end of 1898, the

railroad reached West Usambara and the great mountains of Kilimanjaro and Meru (Gillman, 1942; Illife, 1969; Jack, 1932; McCarthy, 1918).

In parallel to the expansion of German agricultural interests, a taxation system, known as the Hut Tax, was introduced in 1897 (Illife, 1969; Sunseri, 1998). The imposition of the hut, or dwelling, tax forced men to leave their homes and become migrant laborers in distant colonial plantation farms if they could not grow a sufficient quantity of prescribed cash crops, such as coffee and cotton, to pay the tax (Gibbon, 1998; Sunseri, 1993; 1998).

The system of taxation was seen by the Germans as “‘educational’, in that it was intended to oblige Africans to accept paid labor and accustom themselves to European administrative discipline” (Illife, 1969, p. 1154). By 1905 the Hut Tax was raised to a maximum of three rupees per hut.

Through the period 1905-1912, the Germans increased local revenue 33% to 40% through this form of taxation. It is not surprising, then, that the people of Tanganyika had an uprising against the Germans. In 1905, the indigenous people of southern Tanganyika, led by their chiefs, rose up against the cruelty of German rulers in what has come to be known as the Maji-Maji Uprising. Although thousands of Africans died of starvation and the entire south of Tanganyika was devastated, the Maji-Maji struggle has stood out in history as proof that the people of Tanzania have played a role in fighting colonialism (Bell, 1950).

German influence in East Africa ended in 1919. After World War I, Tanganyika became a Mandated Territory under the League of Nations, with the British as the ruling power (Farler, 1889; Morley, 1996; Sensen, 1996). The areas that were to become

Rwanda and Burundi were detached and placed under Belgian rule. Tanganyika formally came under British control in January 1920 when it became a British Protectorate known throughout its 40-year British rule as the Tanganyika Territory (The Encyclopedia of World History, 2001).

**2.2.3. The British Rule.** The British had their own model of colonial administration that they introduced to their newly acquired colony (Dougherty, 1966). Under the British indirect rule policy, local structures were used to control the lives of local people (Dougherty, 1966; Illife, 1969). In 1923, the British introduced the poll tax to replace the German system of taxation (Rogers, 1974).

This system of taxation led to the founding of the Kavirondo Tax Payers Welfare Association and the Kilimanjaro Native Planters Association, which, despite its name, was an association for coffee growers from throughout the whole country (Rogers, 1974; The Encyclopedia of World History, 2001). The activities of the two associations complemented each other.

The Kilimanjaro Native Planters Association worked to ensure that enough coffee was grown for the international coffee market, whereas the Kavirondo Tax Payers Welfare Association supported the collection of taxes from peasant farmers to make sure that the colonial government received its share of their meager income from cash crops (Gibbon, 1998; Ogutu, 1972; Sunseri, 1993; Sutton, 1969).

In 1926, the Native Authority Ordinance was introduced (Dougherty, 1966). Through the Native Authority Ordinance, the British formalized their indirect rule policy (Dougherty, 1966), which meant ruling through the existing structures of traditional rule (Cory, & Hartnol, 1971; Graham, 1976; Ishumi, 1971; Kaijage, 1971; Katoke, 1971;

Ranger, 1979; Reining, 1967; Unomah, 1971). In places that had a feudal system, the British used chiefs (Cory, & Hartnol, 1971; Ironson et al., 1971). Where feudal structures did not exist (i.e., societies that were traditionally egalitarian), they introduced chieftaincy by appointing their own arbitrarily selected chiefs (Cory, & Hartnol, 1971; Unomah, 1971).

Although the country encompassed 132 ethnic groupings, only a few had a developed a feudal structure with kings or chiefs (Cory, 1970; Cory, & Hartnol, 1971; Katoke, 1971; Unomah, 1971). For many ethnic groups, this form of feudalism was a colonial imposition with its own adverse effects on governance at the local level where the decisions that impacted the general welfare of the Africans were made (Graham, 1976; Unomah, 1971). The British replaced the traditional customs and practices of resolving conflict with their own system of law. They turned the indigenous traditions (which otherwise would have changed as society changed) into what has become Africa's nightmare, the 'customary law' (Cory, 1970; Cory & Hartnoll, 1971), which was supposedly meant to accommodate African customs of the time (Cory, 1970; Cory & Hartnoll, 1971; Mesaki, 1993; Unomah, 1971).

Disagreements about land and property ownership were left to the chiefs and clan leadership (Maddox, Giblin, & Kimambo, 1996; Shivji, 1998), and so were the marital and family disputes that these disagreements caused in the newly introduced cash economy (Cory, 1970). The practice of customary law has had adverse effect on the health and welfare of African women and children, in particular. The laws that were introduced by the British were based on the assumption that African customs were static and did not evolve over time.

Africans were at the bottom of that newly created social ladder, which was a form of apartheid. Until independence, the colonial health and welfare systems were mainly run by the Whites, with few Africans serving as support staff. The hospitals had a three-tier system whereby Whites received Grade I treatment and Asians (i.e. Indians) received Grade II treatment (Luthy, 1971; Mamdani, 1969; Sakarai, 1980). Health care for the Africans was generally a matter for traditional healers.

It was not until 1940 that Tanzania had its first African doctor enter government service (The Encyclopedia of World History, 2001). Even after more Africans became doctors and entered government service, the vast majority of African people remained underserved (Illife, 1987; 2001; Lugalla, 1997; Mhamba, & Titus, 2001). To this day, Tanzania has not recovered from this late start (Mesaki, 1993).

### **2.3. Post-Colonial Tanzania**

In 1961, Tanzania became the first East African country to attain independence (Kimambo & Temu, 1969; Legum & Mmari, 1995; Morley, 1996; Raeside, 1996; Sheriff, 1987). In 1929, the Tanganyika African Association was founded; it became the Tanganyika African National Union (TANU) in 1954. The TANU mobilized the people of Tanganyika for independence. While Kenya, its neighbor, was fighting the Mau-Mau war against the British (Brown, 1988), Tanzania was engaging the British in dialogue regarding its promised independence as a Mandated Territory (Dumbuya, 1997; Illife, 1969).

Julius K. Nyerere, often referred to as Mwalimu (teacher), was President from independence in 1961 to 1985, when he stepped down to open doors to a market economy and a multiparty political system (Legum & Mmari, 1995). Tanzania inherited

an economic system from its years of colonial rule that was based on cash crop production oriented toward exporting raw materials to Europe. However, the cash crops fetched less and less in foreign currency as years went by. Thus, the country's post-independence earnings became highly unreliable and, therefore, unsuited for the funding of sustainable development programs (Messkoub, 1996; Tax, 2000; van der Willigen, 1986). Nyerere's government policies were influenced by his adoption of Ujamaa (communalism) and African socialism (Lofchie, 1989; Morley, 1996; Nyerere, 1978; Ottaway, 1987). The policies of Ujamaa fostered self-reliance, while emphasizing the inter-dependence of village members through collectivization (Nabalamba, 2000).

This was a reaction to the individualism that had been introduced into the culture through the colonial policies of forced labor in cash-crop plantations and mining sites. It was also a reaction to the type of taxation that appended women and children to the men who had to pay individual head taxes as well as tax as the head of the household (Austen, 1968; Sutton, 1968). A decade into the Tanzania independence, Nyerere introduced new policies to Tanzania, including universal primary education (UPE). His efforts to increase the population's literacy resulted in an adult literacy rate of 78% (Ferreira, 1996; Galabawa, 1999, Watt, & Rowden, 2002). Although often more blamed than praised for his economic policies, Nyerere merits credit for this success.

Blunt (1999) noted that through Ujamaa and government policies to eradicate poverty through lifelong education, Tanzania's model of democratic socialism restructured the economy and achieved self-reliance. Human development, human capital development, human capacity development, and human resources development are the four concepts that have been credited with Tanzania's success in pursuing adult



education and functional literacy during the second decade of its post-independence years (Blunt, 1999; Buchert, 1997; Kaya, 1989; Van Arkadie et al., 2000).

Despite achievements in areas such as adult education and literacy, Nyerere's critics believed that Ujamaa landed the country in foreign debt to support these aid-dependent, socialist-inspired programs. Although it may indeed be true that its post-independence policies of African socialism slowed down economic progress, Tanzania had other serious problems and constraints to its economic growth. Most of these difficulties were inherent in the economic system that it inherited from the British colonial government (Bigstein & Danielson, 2001; Campbell, 2000; Illife, 1987, 2001; Legum & Mmari, 1995). At independence, the cash crop economic system was maintained, even during the years of experimentation with African socialism.

In 1974, there was an attempt to go beyond Ujamaa (Hyden, 1980) and shift from an agricultural to a manufacturing-based economy (Mbilinyi, 1998). A new economic policy, the basic industry strategy (BIS), was introduced (Tax, 2000). The new policy focused on import substitution and simultaneous expansion of producer goods (i.e., raw and semi-processed cash crops for export) and consumer goods (i.e., import of processed/finished products) (Tax, 2000). However, the experience of Tanzania is that any move made towards recovery from poverty has been reversed by international monetary policies (Rugumamu, 1996; Shivji, 1990; Wangwe, 1998). The BIS soon proved to be so capital intensive and import dependent that it did not help the country's economy.

There were other problems also carried over from the colonial past. These included a poor infrastructure, especially urban infrastructure, to which the country had to

attend (Messkoub, 1996; Rwejuna, 1998). Tanzania also inherited poor health and welfare service systems (Briggs, & Mwamfupe, 2000; Kironde, 1995, 1992). These limited systems, together with other problems facing the country, placed Tanzania at a disadvantage in developing and delivering HIV/AIDS care.

#### **2.4. Health Care and Social Services: Distribution, Delivery, and Implications for HIV/AIDS**

The problem of aid-dependency has been a big stumbling block in Tanzania's efforts to fight the AIDS epidemic efficiently and expediently. Tanzania turned to the existing, poorly funded health and social service infrastructures for her response to the new AIDS epidemic only to find that the country could not respond quickly enough without outside help.

##### **2.4.1. Health Services**

Since independence, health services delivery in Tanzania has been a responsibility of the state and most health service institutions were state owned, with only a limited number of private-for-profit health services. Facilities for health care were re-directed from urban areas towards rural areas, and free medical services were introduced. From 1977 to 1991, the Private Hospitals Regulation, or Act, banned private health services for profit (Health, 2001). By 1995, Tanzania had successfully achieved 80% access to health services, a record that Tanzania's neighbors envied her for (Socialwatch, 1997).

The importance of the private sector in health care delivery was at last recognized in the late 1980s, and the Private Hospitals Act was amended in 1991. The revised Act gave doctors and dentists the right to apply to the Ministry of Health (MOH) for the licensing of a private hospital. Table 1 shows the number of health units in Tanzania (The

Tanzania National Website, 2001), both public and private, but there have been newer private health facilities opened since the table was created and these are not included.

**Table 1 Tanzania Government Owned Health Facility and Agency**

Type of Health Facility	Type of Agency				
	Govt. (Managed)	Govt. (Funded)	Voluntary/ Religious	Private	Others
Consultancy/Specialized Hospitals	4	2	2	0	-
Regional Hospitals	17	0	0	0	-
District Hospitals	55	0	13	0	-
Other Hospitals	2	6	56	20	2
Health Centers	409	6	48	16	-
Dispensaries	2450	202	612	663	28
Specialized Clinics	75	0	4	22	-
Nursing Homes	0	0	0	6	-
Private Laboratories	18	3	9	184	-
Private X-Ray Units	5	3	2	16	1

*Source: Ministry of Health Statistical Abstract, 2001*

The number of such facilities is low and they tend to be located in the major urban centers. It is estimated that there is one traditional healer to every 700 people, which is nearly forty times the number of doctors with MD qualifications available in the country as a whole (Medics Travel, 2000). The medical facilities identified in Table 1 range from village health services to four consultancy hospitals; the services provided at each are described below.

**2.4.1.1. Village health facility.** In rural Tanzania, the health service structure starts with the village health services, which is the lowest level of health care delivery in the country. Each village has a health facility that is managed by two village health workers whose training is equivalent to that of a licensed nurse. These village health workers provide home care services. The village health facility provides only limited outpatient care (i.e. maternal and child health care services). It does not handle cases that need more than an aspirin, bandage, or simple over-the counter malaria tablets, referring those needing further care to the next level, the dispensary.

**2.4.1.2. Dispensary.** A dispensary, on the other hand, cares for up to ten thousand people, depending on the size of the administrative ward. It supervises the village health workers in the village posts below it and is overseen by the medical personnel in the health center above it. The services at this level of health service delivery are very basic and can include emergency admissions while the patient's relatives mobilize transport to get the patient to the next level of health care services, the health center. Expected treatment includes anti-malaria and anti-diarrhea treatment, but a dispensary is only the first stop towards diagnosis and out-patient curative services. Complicated cases must be referred to the district hospital, district designated hospital, or nearest private hospital.

**2.4.1.3. Health center.** The health centers are managed by physician assistants, known in Tanzania as medical assistants, assistant medical officers, or clinical officers. A health center can serve up to 50,000 people, depending on the size of the particular administrative division in the particular district of any given region of Tanzania (The Tanzania National Website, 2001). The services at health centers can include curative services similar to those provided at the outpatient department level of any major

hospital. Maternal and child health services as well as health promotion services are also provided. Anything needing to be done by a doctor with MD qualifications is referred to the next level, the district hospital.

In terms of HIV/AIDS care, health centers and dispensaries have minimum laboratory facilities, including TB, hemoglobin estimation, and blood slide microscopy. “They are also involved in simple clinical chemistry and syphilis screening. At the moment there are no facilities for HIV diagnostic testing at Health Centers and dispensary level” (NACP, 2002, p. 9).

**2.4.1.4. District hospital.** There are twenty regions in mainland Tanzania. Each region has up to six districts and each district has its own district hospital. Most district hospitals are run by the government, but the government may appoint a non-profit health care facility run by a religious organization to be the designated district hospital in districts where the government does not have its own hospital. Some of the district hospitals, especially the designated district hospitals, may have an obstetrician, a surgeon, or a specialist in TB and leprosy. These facilities can handle more complicated medical cases. However, many of the districts hospitals lack diagnostic capabilities, and do not have laboratory or x-ray equipment. HIV screening, at the district hospital level, is based on simple/rapid assay, and there is “no technique for immunological or virological monitoring of HIV/AIDS. Available biochemical tests are also limited” (NACP, 2002, p.8).

**2.4.1.5. Regional hospitals.** Regional hospitals tend to have more expertise and the Regional Medical Officer (RMO) has the power of government to manage the health of a particular region. The RMOs and other doctors stationed at the regional hospitals

respond to the referrals from the lesser health units, but look up to the specialists from the four consultancy hospitals for specialized consultation and up-to-date knowledge on evidence-based medicine for their own continuing education. Some of these regional facilities are better equipped than others, but nearly all of them lack capabilities to perform sophisticated diagnostic imaging.

In terms of HIV/AIDS care, regional hospitals are able to do more than the district hospital, and even some private hospitals. They also have more beds for long-term hospital care. The procedures that regional hospitals are able to carry out are “general microbiological, hematological and parasitological tests... ELISA assays are also done...They lack HIV PCR or CD4+ and CD8+ T lymphocyte determination systems” (NACP, 2002, p. 8)

**2.4.1.6. Consultancy hospitals.** Finally, consultancy hospitals, which serve as national referral health units, are found in each of the four corners of the country. The Dar-es-Salaam-based Muhimbili Medical Centre (MMC) is on the east coast. The Catholic-run hospital based in Mwanza, Bugando Hospital, is in the north-west, along the shore of Lake Victoria. The Lutheran-run Kilimanjaro Christian Medical Centre (KCMC) is in the north near Mt. Kilimanjaro, while the Mbeya Referral Hospital is in the southern highlands.

The country's best and brightest in the field of medicine, both in terms of diagnostic facilities and specialized care, are found at these four centers, with the MMC being the leading one in the nation. Whatever cannot be handled in the country is referred to other countries in East Africa or even abroad (mainly England, but more recently India and South Africa). In terms of HIV testing, all consultancy hospitals are capable of doing

most tests, but “only Muhimbili National Hospital is capable of carrying out CD4+ and CD8+ T lymphocyte subsets determination” (NACP, 2002, p.8). So, all PLHAs who need to know their CD4 count are referred to Muhimbili Hospital.

In theory this arrangement works fine, but, in practice, all these health care units and facilities are under-resourced and under-staffed, which makes it hard for the involved medical team to live up to the ideals of health sector reform (ded-tanzania, 2003; Kiwara, 1995). For a country more than twice the size of California, the list of health care units in Table 1 is not at all impressive.

One thing that must be said, however, is that in the past the distribution of health services was such that every part of the country had access to the health care that was available in the country. Now the free-market economy has tilted the distribution of private hospitals and dispensaries in favor of the few urban centers, including Dar-es-Salaam (Lugalla, 1997). This has left rural areas, which have always been behind (even in good times), very much at the mercy of traditional healers and junior paramedics.

The centralized health care infrastructure also has had serious implications for AIDS care. Initially, neither the districts nor the regions knew exactly what to do for people who presented with AIDS-like symptoms. Without competitive private health care or health insurance to complement government efforts, AIDS was an instant death sentence for many PLHAs because there was nobody to turn to for comprehensive AIDS care (TOMRIC Agency, 2000).

AIDS diagnosis in Africa was, for a long time, based on the nature of the presenting symptoms, an approach endorsed at the 1986 WHO meeting in Bangui,

Central African Republic. To be classified as having AIDS, patients needed to present with two of the following three major signs or symptoms: (1) chronic diarrhea for more than a month; (2) weight loss of 10% of body weight; and (3) intermittent or constant fever for more than a month. The Bangui criteria also specified the following minor signs: history of herpes zoster; persistent cough for more than a month; generalized itchy skin rashes; oral thrush; chronic progressive or disseminated herpes virus infection; and swollen lymph glands (WHO, 1993).

In Tanzania, the Bangui diagnostic guidelines were promoted immediately, despite the fact that by the time such symptom-based diagnoses were made, patients were in the terminal stages of AIDS. As different organizations became interested in AIDS and got involved in caring for PLHAs, HIV testing and AIDS care improved. Tanzania formulated a National Policy on AIDS that included nine objectives for HIV testing and for care of PLHAs (The United Republic of Tanzania, 2001).

By the mid 1990s, management of opportunistic infections improved, and PLHAs were living longer than was the case in the 1980s. However, AIDS care remains hard to finance. There is no social security and health insurance coverage for PLHAs, although some, but not all, employers may pay for their employees' cost of hospital care.

#### **2.4.2. Social Services**

Social services in Tanzania are stretched across different sectors in different ministries. The four ministries having the greatest role in social service delivery are: the Ministry of Agriculture and Food Security; the Ministry of Community Development, Women and Children; the Ministry of Education and Culture; and the Ministry of Labor, Youth, and Sports Development, which includes Social Welfare. Other ministries may



include a component of social service in their mandate, but these four ministries are the key ones that could directly impact HIV/AIDS infected and affected people.

**2.4.2.1. Ministry of Agriculture and Food Security.** The Ministry's stated vision and mission involves a commitment to ensure that the country has commercially viable, highly competitive and diversified food security that will improve rural livelihood. It is also committed to expanding rural employment, while stimulating economic growth and linkages between different sectors. The Ministry pursues these aims by utilizing natural resources in a sustainable manner (The Tanzania National Website, 2001).

In rural Tanzania, sustainable growth in agricultural is dependent on subsistence farming (Gibbon, 1998; Mbilinyi, 1998; Sutton, 1969; Tibaijuka, 1988). Since the beginning of the AIDS epidemic, subsistence has been compromised by high AIDS-related death rates in farming community households. Given that social services to reduce the impact of AIDS on the peasant farmers are inadequate (Beegle, 1997), the Ministry of Agriculture has an important role in the multi-sectoral policy framework, advising The Tanzania Commission for AIDS (TACAIDS) on policies to ease the burden of lost farm labor when time spent on care, funerals, and mourning detracts from time spent on cultivating, harvesting, and processing food crops (Mujinja, & Over, 1995).

**2.4.2.2. Ministry of Community Development, Women and Children (MCDWC).** This is a key ministry on policies that directly affect women and children. Its vision for Tanzania is to have communities that are mobilized to be gender sensitive and equipped with the capacity to identify factors that encourage or constrain improvements in the quality of life, both socially and economically (The Tanzania National Website, 2001).

Formulating gender-focused policies and creating an enabling environment to empower both men and women in all communities is the strength that this ministry brings to the multi-sectoral team coordinated by TACAIDS.

Since unsafe sex remains a problem (Bujra, 2000), and high adult mortality continues to leave children without protection (Kaijage & Tibaijuka, 1996; Karanja, 2002), the Ministry has played an advocacy role in persuading other sectors to focus on the vulnerability of women and children in their policies. Also, after noting that despite widespread awareness of HIV/AIDS, efforts were still limited to fostering safer sexual behavior and to reducing the discrimination and stigmatization of those with HIV/AIDS (Galabawa et al., 2001), the Ministry began collaborating with other sectors to integrate HIV/AIDS treatment and prevention activities into a policy framework (TACAIDS, 2002).

**2.4.2.3. Ministry of Education and Culture.** This Ministry sees Tanzania as having the potential to be a nation with a high level of education, producing people sufficiently equipped with the requisite knowledge to solve the society's problems, meet the challenges of development, and attain competitiveness at regional and global levels (The Tanzania National Website, 2001). Its main mission is universal primary education (UPE) and the eradication of illiteracy. The Ministry is also committed to fostering the types of higher education and training needed to produce the high quality human resources required to effectively respond to the development challenges (The Tanzania National Website, 2001). The Ministry has realized that for children and adolescents who have lost parents, it is not enough to provide free primary education if other conditions that lead to poor school attendance and/or dropping out of school are not addressed.

Many community-based organizations are working closely with schools to support orphans so that they stay in school (Galabawa et al., 2001; TACAIDS, 2002).

**2.4.2.4. Ministry of Labor, Youth, and Sports Development.** This Ministry seeks to improve the work environment; to promote effective social welfare conditions for the people; to create a good working environment, and to foster well brought up and responsible youth in society with the mission to promote labour standards, employment, social welfare and youth who are capable of taking their place in and contributing to (The Tanzania National Website, 2001). This can be considered a key ministry for social services.

The social welfare department within the Ministry is usually the least funded. Therefore, it concentrates its efforts on services for the disabled and destitute, rather than directing its efforts towards policies for social service delivery and the general welfare of the public. Recently, however, it has played an active role in developing child welfare and orphan protection policies (Kaijage & Makbel, 2003).

The labor development section has worked with International Labor Organization (ILO) to regulate labor laws for workplace safety and employment security (Monyo, 1999). However, a recent report projected a severe decline in the size and quality of the workforce in the sub-Saharan Africa region (ILO, 2000), mainly due to HIV/AIDS. The Ministry is working with other sectors to ensure that there are HIV/AIDS support and prevention programs at workplaces (TACAIDS, 2002). Failure to adequately address universal social security coverage and health insurance to meet the cost of AIDS care has been a major shortcoming in the Ministry's vision (Socialwatch, 1997).

## **2.5. HIV/AIDS in Dar-es-Salaam**

Dar-es-Salaam has an estimated population of almost 3 million. The three municipalities that constitute the city of Dar-es-Salaam, i.e., Ilala (637,573), Kinondoni (1,088,867), and Temeke (771,500), have a total population of 2,497,940 (Dar-es-Salaam Municipal Council Diflucan Program, 2003). The city has the highest case rate (estimated at +/- 20%) in the country (Catholic Relief Services, 2000). Due to widespread poverty (Galabawa, 1999; Kironde, 1995), urban life is as hard as rural life for a PLHA living in Tanzania today (Lugalla, 1997), but it is mainly the problem of overcrowding that makes urban living so difficult (Tibaijuka, 2002). Moreover, despite the many organizations that have addressed AIDS issues at the national level (i.e., AMREF, Kuleana, NACP, PASADA, TACAIDS, TAMWA, TGNP, SHDEPHA+, and WAMATA), HIV testing and counseling services have not been systematically provided and condoms have been neither free nor affordable for all that need to use them.

Even where services have been made available, few people have information about them or are guided on how to access these services. In Dar-es-Salaam, few people go to the dispensary or hospital to see a health professional for prevention (Mhamba, & Titus, 2001). Consultation by telephone is even rarer due to limited access to telecommunication services. Thus, PLHAs depend on such ASOs as SHDEPHA+, WAMATA, and similar organizations for most of their health care services.

For people who are employed, most work sites have a health clinic that serves as a point of entry into the formal health care system. Some of these work-based health clinics are better equipped than others, but few of them have adequate facilities to serve PLHAs comprehensively. However, the bigger or more prestigious ones are more likely to provide specialized care to their patients.

For example, the University of Dar-es-Salaam's Health Center is managed by an ophthalmologist, and has an obstetrician and a pediatrician on its staff. It serves both the university community and the community surrounding the university. It admits PLHAs as patients and has, in the past, worked with WAMATA on counseling the families of PLHAs who were in the terminal stages of AIDS.

As for the unemployed among the city's population, there are public and private dispensaries in each of the city's 73 administrative wards. However, since the 1990s when, in the name of cost-sharing, user fees were introduced as part of the health sector reform (Kiwara, 1995; Watt, & Rowden, 2002), most people use these health care services only in cases of medical emergency.

Each of the city's three municipalities oversees one major hospital. The hospitals are: Amana (150 beds) for Ilala, Mwananyamala (160 beds) for Kinondoni, and Temeke (120 beds) for the municipality of Temeke. Between them, the three hospitals have an average of up to 100,000 out-patient visits per year (Dar-es-Salaam Municipal Council Diflucan Program, 2003). Table 2 presents the number of known HIV patients treated at these three hospitals during 2003 (Dar-es-Salaam Municipal Council Diflucan Program, 2003).

According to the Municipal Medical Officer (MMO) (2003), Kinondoni is different from other municipal councils and other districts in the country in terms of the range and quality of the health services available. The MMO cited as an example the Municipal/District Hospital Mwananyamala, which has services that are equivalent to those of a regional hospital (personal communication, Dr. Beatrice Byarugaba, Kinondoni MMO, November 12, 2003). However, Dr. Kokuhumbya Kazaura, the

**Table 2 HIV+ Patients Treated in Dar-es-Salaam Municipal Hospitals in 2003**

Municipal Hospital	Municipal Council	Adults	Children	Total
Amana	Ilala	12,417	1,380	13,797
Temeke	Temeke	5,700	600	6,300
Mwananyamala	Kinondoni	13,533	1,533	14,066
Total		31,650	3,513	34,163

Municipal AIDS Coordinator (MAC) of Kinondoni, said that HIV/AIDS services were not comprehensive (personal communication, November 14, 2003). In particular, there is not an adequate supply of drugs (personal communication, Dr. Kokuhumbya Kazaura, November 14, 2003).

Hence, the quality of service is relative. As of June 2002, Mwananyamala Hospital alone had 2,233 patients in HIV counseling. Seventy-six percent of these, or 1690 patients, agreed to test for HIV, and 534 of them tested positive (Kinondoni Municipal Council, 2003, p. 19). Considering that there is more voluntary HIV testing taking place in private health care facilities than in Mwananyamala Hospital alone (personal communication, WAMATA ARV counseling team, October 29, 2003), Kinondoni may have more HIV+ residents than appears in its comprehensive health plans. Thus, available resources may not be sufficient to provide for all who may need care.

## **2.6. Summary**

The HIV epidemic is threatening to reverse all the gains that Tanzania has made throughout her struggles during the pre-colonial, colonial, and post-independence periods. Tanzania, which has historically been so disadvantaged, has not been able to provide adequate economic, medical, psychological support to PLHAs and their families. History is still being made in Tanzania, and HIV/AIDS is shaping today's history.

### **3. CHAPTER THREE: THEORY**

Theory is, perhaps, one of the most intriguing aspects of science. Theory has at times been said to be imperfect fact (Gould, 1981, Moran, 1993). According to Popper (1962), facts only begin to “exist as facts” after “they are singled out from the continuum of events and pinned down by the statements--theories that describe them” (p. 290).

Moran (1993) saw theories as structures of ideas that are used to explain and interpret facts. To Gould (1981), theory is part of a hierarchy with an intelligent guess at one end of the spectrum and theory at the other, with hypothesis in the middle while to Popper (1963), theory must be testable and falsifiable. The scientific status of theory, argued Popper (1963), is its falsifiability or refutability. Darwin (1959), too, expected his theory of evolution to be challenged by those whose disposition led them to attach more weight to unexplained difficulties than to the explanation of facts presented in the theory.

As for Kuhn (1962), he believed that there was no absolute truth. According to Kuhn (1962), there was no theory that could explain all things. Hence, theory evolves in search of truth, and scientists agree that theory calls for research to test it (Burchfield, 1990; Darwin, 1859; Gould, 1981; Kuhn, 1962; Moran, 1993; Muller, 1959; Popper, 1963). So, without research and hypothesis testing, there is neither theory nor progress.

While the preceding chapter discussed the historical events that have led to the present situation of HIV/AIDS in Tanzania, this chapter discusses the theories that guided this study. The chapter begins with a review of stress theory and then moves on to discuss social support theory. Following that, the theory of health locus of control is discussed. The chapter concludes with a presentation of the study’s hypotheses that have been derived from these theories.



### **3.1. Stress Theory**

Stress has such an influence on one's health and one's functioning that it can be expressed through both emotional and physical ways (Atkinson & Grant, 1994; Eaton, 2001; Elliott, & Eisdorfer, 1982; Gore, Aseltine, & Colton, 1992; Holmes & Rahe, 1967; Linn, Monnig, Cain, & Usch, 1993; Rosengard, & Folkman, 1997; Schutte, 2002). Often the former occurs when a specific situation is perceived as being too difficult to manage, while the latter occurs as a physiological reaction of one's body to a difficult experience (Antonovsky, 1987; Ballieux, 1984; Coyne, Aldwin, & Lazarus, 1981; Hunt, 1996; Kiecolt-Glaser, Cacioppo, Malarkey, & Glaser, 1992).

According to Gershaw (1992), stress is any stimulus that upsets the dynamic balance of a person's body, which stress theorists have defined in terms of stimulus-response-stimulus (Lazarus, 1966; Lazarus & Folkman, 1984; Thoits, 1995). Interactions between people and their environment, or among people, may, at times, be perceived by the individual experiencing the interaction as being stressful or threatening (Holmes & Rahe, 1967; Lazarus & Folkman, 1984; Wheaton, 1983).

There is constant adaptation to accommodate the stress arising from interaction processes, and many stress theorists argue that stress is unavoidable in everyday life (Pearlin & Skaff, 1995). Rather, it is often how one copes with, or handles, stressors that provide evidence as to whether one has moderate or excessive stress (Aneshensel, 1992; Hofer, 1999; Holmes & Rahe, 1967; Lazarus & Folkman, 1984; Oakland & Ostell, 1996; Pearlin, & Schooler, 1978; Wheaton, 1983). Thoits argued that it is by responding to the daily challenges of life that people's stress load is assessed. Stress can be determined through primary appraisal, which is a cognitive evaluation of the threats associated with a

difficult event, or through secondary appraisal, which is the assessment of resources to cope with the perceived threat (Selye, 1956; Wheaton, 1983).

Coping resources vary from one individual to another and from one situation to another. Coping resources can be either internal (e.g., emotional) or external (e.g., financial) (Aneshensel, 1992). The results of a study by Koopman and colleagues (2000) indicated that HIV-positive persons with lower incomes perceived greater stress in their daily lives than those with higher income, illustrating the importance of external coping resources. Reflecting the centrality of internal coping resources, the study also found that perceived stress was greater among those who reported more anxious or less secure attachment styles as well as those who reported greater use of behavioral or emotional disengagement strategies for coping with HIV/AIDS.

At a macro level, the socio-political environment can influence social policies that could either enhance coping resources or exacerbate stress (Brown, 2000; Cain, 1997; Kalichman, Sikkema, DiFonzo, Luke, & Austin, 2002). In support of the argument for the influence of macro factors on stress, Sen (1999) argued that what people can positively achieve is “influenced by economic opportunities, political liberties, social powers, and the enabling conditions of good health, basic education, and the encouragement and cultivation of initiatives” (p.5).

According to Sen (1999), the institutional arrangements giving rise to these opportunities are also influenced by the exercise of people’s freedoms, by their liberty to participate “in social choice, and in the making of public decisions that impel the progress of these opportunities” (Sen, 1999, p. 5). That is why it was important to discuss

the social history of Tanzania as a starting point for framing current HIV status stress among Tanzanian PLHAs.

### **3.1.1. Stressors**

There are several types of stressors: daily hassles, stressful life events, chronic stressors, traumatic events, chronic community stressors, and non-events (Thoits, 1995; Moroka, 2003). A case can be made that all the above stressors apply to persons with HIV/AIDS, but it is chronic stressors that are of particular interest to this study since they represent persistent events that cause substantial strain on the individual (Decker, 2001; Leserman, 2000; Zaleski, Levey-Thors, & Schiaffino, 1998).

While acute stress may involve an encounter with a situation that poses immediate threat to one's well being (e.g., waiting for HIV test results), chronic stress involves ongoing stressful situations (e.g., the loneliness that is common among PLHAs). Coping with a chronic stressor requires major readjustments and replenishments of one's psychosocial resources so as to facilitate adjustment to a sustained change in one's behavior and lifestyle (Cohen, & Edwards, 1989; Leserman, Perkins, & Evans, 1992; Wight, 1998; Zich, & Temoshok, 1988).

In fact, the experience of being diagnosed with HIV infection alone is stressful (Arrindell, 2003; Green, & Sobo, 2000; Leserman et al., 1999b). While the HIV diagnosis can be both a stressful life event and a traumatic event, the life-long experience of living with an HIV diagnosis is a chronic stressor (Beaudoin, 1992; Cohen, Kamarck & Mermelstein, 1983; Wight, 1998). This is the kind of stress that is ongoing, long term, and persistent over a long period (Nidus Information Services, 2001). Moreover, the members of the households and the communities of PLHAs often experience chronic

stressors as well (Battles, & Wiener, 2002; Beegle, 1997; Kadushin, 1999; Lay, 2001; Millen, 2003).

### **3.1.2. HIV Status Stress**

A study investigating stigma among PLHAs in Ethiopia, Tanzania, and Zambia was recently conducted by Nyblade and colleagues (2003). The study found that stigma-related and discrimination-related stress impeded prevention of HIV/AIDS (Nyblade et al., 2003). In fact, it is the stress associated with acts of prejudice and discrimination that gives AIDS activists and human rights activists cause for concern (Berger, 1998; Uthis, 1999).

Past stress studies have show that it requires adaptation (Coyne, Aldwin & Lazarus, 1981, Dubos, 1965; 1978; Fine, 1991; Kang, 2002; Sikkema, 1998; Wortman, & Conway, 1985). Stress theory has, therefore, incorporated such moderating and buffering factors as coping resources, coping strategies, and social support (Hofer, 1999; Hutchison, 1999; Josephson, 1997; Koopman et al., 2000), all of which may apply to the situation of the PLHAs in Tanzania as they have shown to apply to the PLHAs elsewhere in the world (Arrindell, 2003; Benedict, 1996). Whether coping with stress will, indeed, positively or negatively influence PLHAs' appraisal of stress will depend, as it does in most cases, on the factors at play in each specific situation for each person at any given time and place (Farmer & Kleinman, 1989; Hofer, 1999; Greenberger, Chen, Tally, & Dong, 2000; Schwartzberg, 1993). Receiving results of a test for the antibodies for human immunodeficiency virus (HIV) can be regarded as a stressful life event for those at risk (Hofer, 1999). Individuals experience a lot of stress both before making the

decision to test and after testing while waiting for their test results (Blaney et al., 1997; Leiphart, 1998).

Research on coping behavior as well as associations of coping with psychological distress in 172 bereaved HIV sero-positive and sero-negative gay or bisexual men concluded that an HIV sero-positive status was significantly associated with increases in distressed mood (Burkhalter, 1997). In other words, losing a loved one due to HIV/AIDS brings the stress that the bereaved has been experiencing all along to its peak. Research on distress has also shown that stress can increase physical symptoms (Compas, & Grant, 1993; Decker, 2001; Zaleski, Levey-Thors, & Schiaffino, 1998). Such symptoms include psychosomatic disorders which, in HIV/AIDS, can include severe pains in the joints and muscle-aches (Zaleski, Levey-Thors, & Schiaffino, 1998).

A study of pessimism and emotional repression in the progression of HIV-related gynecological conditions in HIV-1 seropositive black women concluded that a greater number of negative life events was associated with higher levels of progression, persistence, or repeated outbreaks in some of the conditions that were measured (Pereira, 1999). According to these findings, interventions should focus heavily on exploring the mechanisms of coping with stressors, both those related and unrelated to HIV (Pereira, 1999). The negative impact of stress on people living with HIV has drawn the attention of many researchers (Ironson et al., 1994; Nanin, 2001).

Some studies have shown that it is not unusual for long-term debilitation to result in stress (Nanin, 2001). Although some studies on the effects of stress, depressive symptoms, and social support on the progression of HIV infection have found faster progression from HIV to AIDS to be associated with more cumulative stressful life

events, more cumulative depressive symptoms, and less cumulative social support (Leserman, 2000; Leserman et al., 1999), these studies did not support the view that an increase in stress and a decrease in social support significantly predicted the PLHA's progression from HIV to AIDS (Buchbinder, 1994; Leserman, 2000; & Leserman et al, 1994, 1999). However, to show if stress is indeed not a co-factor in contributing to the early deaths of African PLHAs, similar studies are needed on African PLHA populations.

As to whether stress affects any other areas of the socio-biomedical functioning of PLHAs in a significant way (Farmer & Kleinman, 1989; Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998), future studies on African PLHAs are needed so as to establish whether there are levels of vulnerability in the African population of PLHAs for whom limited access to modern biomedical interventions may be yet another source of stress.

A study by the Canadian Vanguard Project showed that HIV-infected men who have sex with men (MSM) are at a high risk for secondary infection if they had experienced sexual abuse in their childhood (Schilder et al., 2000). These findings support the view that HIV-infected MSMs are prone not only to primary HIV infection (i.e. being infected for the first time or infecting other people), but also to secondary HIV infection (i.e. causing re-infection to self and others), if they were sexually abused or raped as children (Kalichman, Sikkema, DiFonzo, Luke & Austin, 2002; Schilder et al., 2000; Schilder, Kennedy, Strathdee, Goldstone & O'Shaughnessy, 1999). These findings suggest that the effects of any type of stress that has not been previously addressed will emerge as a later barrier to primary and/or secondary HIV prevention in all PLHAs, whether gay or not, and whether they live in Africa or anywhere else in the world.

Stress can also act as a barrier to treatment adherence. A French prospective, controlled randomized trial involving a group that received a counseling intervention found that the counseling intervention resulted in lowering stress and increasing the ability of PLHAs to develop self-care management skills that improved their adherence to treatment (Bentz et al., 2002). Research sponsored by the US Centers for Disease Control and Prevention, conducted in one of three inner-city New York City hospitals, found that HIV-infected pregnant mothers who were experiencing stress were unable to follow the prescribed dosing schedule and were embarrassed or otherwise reluctant to admit this during follow up interviews for their neonate infants (Demas, 2002).

A study of healthy men infected with HIV for more than 10 years found that accepting the diagnosis, but refusing to see it as a death sentence, and being able to communicate openly on subjects, including HIV, were important factors in living long with the virus (Buchbinder et al., 1994), and these increase with social support. PLHAs need support in balancing the goals of living long productive lives with preventing further HIV transmission (Chen, Phillips, & Kanouse, 2001; Koopman et al., 2000).

### **3.2. Social Support Theory**

The roots of the concept of social support are found in such nineteenth century sociologists as Durkheim (1984), who established a link between diminishing social ties and an increase in suicide (Durkheim, 1984; Rawls, 1997; Vaux, 1988). As a concept, it has evolved over time starting with the terms “social ties,” as used by Durkheim (Vaux, 1988), and “social system,” as described by Caplan (1974), to what is now social support, which has different dimensions to it and is expressed in different forms and different ways. It can come in the form of emotional support from family, friends and peers

(Greenberger, Chen, Tally, & Dong, 2000; Liang, Gu, & Krause, 1992), as well as from social interactions in the community (Brashers, 2002; Burkhalter, 1997), including with professionals, and even from interaction with the environment (Gottlieb, 1983; Gottlieb, 1988).

Frank and Mustard (1994) argued that social support results in a sense of achievement, higher self-esteem, and control over one's work and one's life, all of which affect one's health and well-being. In many ways, both the giver and the receiver of social support benefit from this give-and-take process. According to Taylor, Sylvestre and Botschne (1998), social support is a process of people negotiating meaning together through their interactions within relationships.

Social support theorists have debated whether social support should be best understood in terms of (1) networks of personal relations, (2) preventive or therapeutic commodities, (3) interpersonal coping resources, (4) personality characteristics (i.e., perception, appraisal), (5) a social provision, or (6) an interpersonal communication (Taylor, Sylvestre, & Botschne, 1998). However, none of these alone captures the transactional dynamism that brings coherence to the inter-connectedness among all these components of social support (Botschner, 1996; Folkman, 1984; McCormick, 1995). Cohen and Wills (1985) contended that whether support is measured in terms of structure or function, there is a distinction among the various types of support, i.e. emotional, informational, social companionship, and instrumental.

Cohen and Wills (1985) argued that social support gives individuals the positive context within which experiences of stressful events are processed. Barrera (1986), on the other hand, made a distinction between social embeddedness, perceived support, and



enacted support, defining social embeddedness as a state of connectivity, of being a part of social groups or of being effectively integrated within social networks. Perceived social support is seen as the cognitive appraisal of being reliably connected to others (Moody & White 2001), while enacted support is the actual support received. It is this sense of assurance that McCormick (1995) referred to as one's satisfaction with social relationship, which has intrinsic, as well as instrumental, value (Cohen & Wills, 1985; McCormick, 1995; Rook, 1987).

Like Barrera (1986), Sarason, Sarason and Pierce (1990) and Schwarzer and Leppin (1991) have distinguished between perceived and received support, observing that the difference between perceived and received support is that one is a cognitive type of support, or cognitive appraisal of what support is available to an individual, while the other is behavioral type of support, or actual support received (Paton, 2002).

Although it has been shown that healthy individuals who are socially embedded or those who perceive themselves to be socially supported are self assured, loved, accepted, and socially included (Sarason, Shearin, Pierce, & Sarason, 1987), it is also true that it is the actual support received or enacted during the times of crisis that makes a difference in the life of the person caught in the middle of the crisis situation. According to Barrera (1986), it is the extent to which one can reliably count on one's network of support to step in to provide the required support that defines perceived social support.

The quality of the relationship between the person who gives and the person who receives is also important. It provides the social context within which social support takes place. There is reciprocity in the relationship between the person perceiving that support will be given and the person that is expected to give support (Barrera, 1986). Paton

(2002) argued that the presence of extensive social ties and interactions did not necessarily translate in support being given. According to Syme (1994), one's socioeconomic class determines both one's network of support and one's actual support.

Pearlin (1989) also saw one's social status as an important factor in determining the level of social support that one is likely to either perceive or receive. The lower the social class, the less the control one has over one's destiny (including one's source of support), and the less the ability one has to influence the events in one's life, including the events that affect one's health (Syme, 1994).

Control of destiny involves access to a variety of things, including financial resources, power and prestige, and information (Syme, 1994). A combination of all these things could lead to a feeling of mastery, self-efficacy, locus of control, predictability, desire for control, sense of and ability to control, hardiness, competence and better health (Syme, 1994). Social support increases overall positive affect and elevates senses of self-esteem, stability, and control over the environment (Bandura, & Walters, 1963; House, Landis, & Umberson, 1988).

It is individuals with high feelings of control, who unlike those with low self-esteem, focus on active coping and on problem solving (Leserman, Pekins, & Evans, 1992; Thoits, 1995). All this has direct relevance to HIV/AIDS, especially in underserved populations and in underdeveloped communities where poverty undermines people's sense of mastery and control. Adaptation to stress, or having a sense of coherence (Antonovsky, 1987), is dependent on multiple factors in the social world (McCormick, 1995), including, among other things, relationships with other people and also with the environment (Leserman, 2000). These relationships give social support a context within

which it is given and received as well as interpreted by both the person providing it and the one receiving. Paton (2000) considered the following three models of social support as important hypotheses:

- (a) the moderator or buffering model,
- (b) the direct or main effects model, and
- (c) the mediating model.

As the above discussion suggests, the link between adherence and the perception that social support will be available as well as actually received is complex and hard to quantify (Barrera, 1986; Cobb, 1976; Hutchison, 1999; Paton, 2000). The most important thing, however, is that both perceived and received support are important determinants of adherence to any treatment regimen pertaining to any health condition (Koopman et al., 2000).

### **3.2.1. Stress and Social Support in HIV/AIDS**

Findings from an assessment of the need for care and prevention for persons living with HIV in New Hampshire indicated that there were challenges, but also opportunities, for health care and social service providers to integrate prevention messages into health care settings (Perlmutter, Clark, Mangione, Ayotte, & Kessler, 2001). According to the study, there were gaps in the way support and prevention were integrated into HIV risk reduction programs, including how social networks of PLHAs and their families were integrated into short-term and long-term counseling programs.

A cross-sectional study, which was based on the buffering and diathesis-stress (predisposed to stress) models, sought to predict hopelessness among a sample of 50 HIV+ mothers who were interviewed in outpatient medical clinics in Chicago (Wyatt,

1997). Social support was found to be pivotal in combating hopelessness among these respondents.

Past research on primary and secondary HIV prevention in the developing world has shown that social support may buffer stress (Kelly & Kalichman, 2002). However, further research is needed to specify the types and amounts of social support needed by PLHAs to buffer HIV status stress such that it would be possible for them to protect themselves and prevent primary and secondary HIV infection.

The direct effect hypothesis involves assuming that the presence of social support directly impacts the dependent, or outcome, variable. Brashers (2002) conducted a study of 30 HIV-infected people who reported being members of an AIDS activist group. The investigation compared them to 144 other HIV-infected people who were not involved in such a group. The study results revealed that participation in AIDS activist groups made a difference in creating social and personal behavioral change. Those involved in an AIDS activist group felt more supported, so they were more likely to make action plans and/or adhere to schedules instead of engaging in wishful thinking in the hope that their problems would go away (Brashers, 2002). In addition, those who had social support from groups, compared to those who did not, showed greater awareness and use of HIV/AIDS information resources (Brashers, 2002).

In a qualitative study that explored the care and prevention needs of persons living with HIV in New Hampshire, the participants reported turning to health care providers for informational support on reducing HIV re-infection and transmission (Perlmutter, Clark, Mangione, Ayotte, & Kessler, 2001). In Zimbabwe, results from a study by Meursing and Sibindi (2000) showed that supportive counseling for the social

and emotional needs and problems of newly diagnosed seropositive patients attending public health services go beyond the pre-and-post test phase.

Supportive, ongoing counseling is able to assist newly diagnosed PLHAs in meeting needs and addressing problems which appear over time. PLHAs are able to replace fear-inducing HIV campaigns with interactive, constructive information about HIV prevention and care (Meursing & Sibindi, 2000). These studies suggest, therefore, that supportive counseling establishes supportive interactions with clients so that, over time, they begin to perceive care providers as part of their support network (Kalichman, & Sikkema, 1996; Lie & Biswalo, 1994; Oumtane, 2001; Uthis, 1999).

A study by Coates and colleagues (2000) reported positive results from a brief intervention that combined HIV testing, sero status feedback, risk-reduction counseling, and condom provision for individuals and sexual-partner dyads in Kenya, Tanzania, and Trinidad. The study enrolled more than 4,000 participants who were randomly assigned either to the counseling and testing intervention or to a health-education control group. After seven months, the proportion of HIV counseling and testing participants who reported unprotected intercourse with non-primary partners declined by 35%, relative to a reduction of 13% among controls (Coates et al., 2000).

The results demonstrated how combining HIV testing with counseling can be an effective strategy to increase adherence to HIV/AIDS treatment and prevention. This effect could partly be attributed to the ability of counseling to enhance the PLHAs' social support, which, in turn, may lead to enhanced internal health locus of control, thus enhancing the PLHA's adherence to HIV/AIDS treatment and prevention (Hirsch, 1981; Leiphart, 1998; Olson, 1995).

### **3.3. Health Locus of Control**

Locus of control is described as the way individuals see themselves as being in control of their own destiny, or being responsible for their course of actions, irrespective of whether their actions are desirable or undesirable (Dirkes, 1988; Greenglass, Schwarzer, & Taubert, 1999b; Lefcourt, 1976; Phares, 1976; Vygotsky, 1978). The concept of locus of control is an extension of, or originates from, the social cognitive theory advanced by Bandura and Walters (1963). Lefcourt (1976) argued that locus of control could be linked to such other constructs as learned helplessness (Peterson, Maier, & Seligman, 1993), as used in psychiatry, or alienation, as used in sociology, and self-image or self-esteem, which are commonly used in psychology.

The multiple dimensions inherent in the locus of control have been of interest to researchers. When measured alone, locus of control was such a limited construct that it did not adequately measure health behavior. In response to this inadequacy, Wallston and colleagues (1976) added a new dimension to locus of control, health. They called it health locus of control.

Health locus of control is the degree to which individuals believe that their health is controlled by internal or external factors. Whereas internal locus of control is the belief that an outcome is directly the result of one's behavior, external locus of control is the belief that an outcome is under the control of powerful others or is determined by fate, luck, or chance. Hence, people with an internal health locus of control are not inclined to be easily influenced by the opinions of others, while people with an external health locus of control will most likely blame outside circumstances for their mistakes, or credit their successes to chance and luck rather than to their own efforts.

Rotter (1966) devised the Internal-External Locus of Control Scale (I-E). Many studies have since found that this measure is a valid predictor of behaviors that are typically associated with locus of control (Greenglass, Schwarzer, & Taubert, 1999b; Lefcourt & Davidson-Katz, 1991, Santiago & Okey, 1992). Wallston, Wallston, Kaplan and Maides (1976) recognized the difficulties in predicting health behavior from generalized expectancy measures such as Rotter's I-E scale, so they developed a locus of control measures specific to health. The earlier scale by Rotter (1976) was used to measure generalized locus of control beliefs known as IPC (I – Internal, P - Powerful Others, C – Chance). Walllston and colleagues combined their scale with Rotter's scale into a single, multidimensional health locus of control scale, the dimensions of which are summarized below:

1. Internal HLC (IHLC) is the extent to which one believes that internal factors are responsible for health/illness.
2. Powerful Others HLC (PHLC) is the belief that one's health is determined by powerful others
3. Chance HLC (CHLC) is the belief that health illness is a matter of fate, luck, or chance.

Kang (2002) examined the relationships among uncertainty, seriousness of illness, social support, appraisal of uncertainty, health locus of control, and perceived health status in patients newly diagnosed with atrial fibrillation. The study found that internal health locus of control moderated the effect of uncertainty on appraisal of danger, thus lowering the impact of stress arising from uncertainty (Kang, 2002).

The multidimensional health functioning of the minority populations, however, has not been given much attention, especially as far as dimensions pertaining to mental health and HIV/AIDS are concerned (Dew, Ragni & Nimorwicz, 1990). Carey and others

(2000) studied the psychosocial stress and health status of inner city minority HIV+ clients. Their study suggests that the complex regimen of HIV treatment adds to other stressors over time. The authors conclude that the stress and multidimensional health functioning of minorities living with HIV/AIDS have so far been understudied.

### **3.4. Study Hypotheses**

In my view, being diagnosed with HIV or having HIV progress to AIDS should be as stressful as being diagnosed with any other previously studied chronic illness (Kleinman, 1988; Schlebusch & Cassidy, 1995; Schwartzberg, 1993; Selye, 1956). However, the stigma that has come to be associated with HIV/AIDS (Nyblade et al., 2003; Temba, 1997), unlike the stigma associated with other chronic illnesses, makes HIV status stress unlike any other type of stress. A stigmatized PLHA may be too overburdened with stress to assume responsibility for being HIV positive and to take the next step of positively seeking and adhering to AIDS treatment and HIV prevention (Lesserman, 2000; Leserman et al., 1999; and Nyblade et al., 2003).

To do that requires that the HIV-infected person seek and obtain social support to buffer the impact of HIV status stress. Moreover, a person's health-related locus of control may mediate the impact of both HIV status stress and social support on adherence to treatment and prevention regimens. Therefore, I hypothesize that:

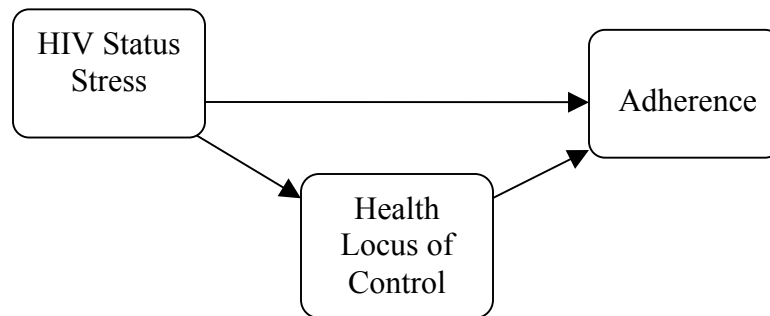
#### *Hypothesis 1*

Hypothesis 1a: There is a direct relationship between HIV Status Stress and adherence to HIV treatment and prevention.

Hypothesis 1b: There is a direct relationship between HIV Status Stress and rejection of chance health locus of control.



Hypothesis 1c: Rejection of chance health locus of control mediates the relationship between HIV Status Stress and adherence to HIV treatment and prevention.



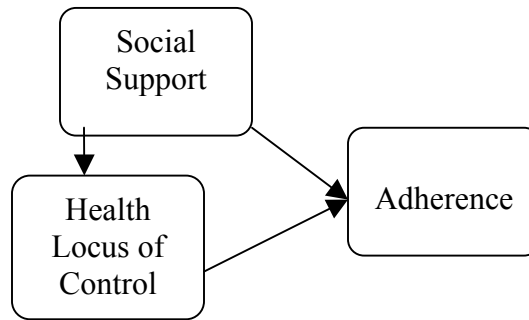
**Figure 2 First Mediation Model: Internal health locus of control mediating the relationship between HIV stress status and adherence to HIV/AIDS treatment and prevention**

### *Hypothesis 2*

Hypothesis 2a: There is a direct relationship between social support (Informal and Formal) and adherence to HIV/AIDS treatment and prevention.

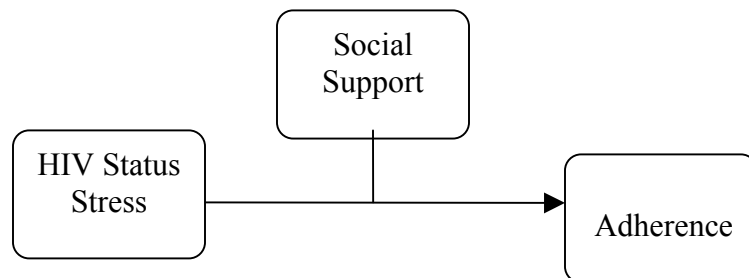
Hypothesis 2b: There is a direct relationship between social support (Informal and Formal) and rejection of chance health locus of control.

Hypothesis 2c: Rejection of chance health locus of control (HLCRCH) mediates the relationship between social support (Informal and Formal) and adherence to HIV/AIDS treatment and prevention



**Figure 3 Second Mediation Model: Health locus of control mediating the relationship between social support and adherence to HIV/AIDS treatment and prevention.**

*Hypothesis 3:* Social support (Informal and Formal) moderates the relationship between HIV status stress and adherence to HIV/AIDS treatment and prevention.



**Figure 4: Moderation Model: Social support buffering the relationship between HIV/AIDS stress status and adherence to HIV/AIDS treatment and prevention.**

#### **4. CHAPTER FOUR: METHODOLOGY**

This study focused on the factors influencing adherence to HIV/AIDS treatment and prevention among Tanzanians living with HIV/AIDS in Dar-es-Salaam. Stress theory (Lazarus, 1966, 1980), social support theory (Cobb, 1976; Cohen, 1993; Cohen & Edwards, 1989; Cohen, & Wills, 1985; Sarason, Sarason, & Pierce, 1990), and the theory of health locus of control (Wallston, 1993; Wallston et al., 1983; Wallston, Wallston, & DeVellis, 1978) guided the development of this study's model and its hypotheses.

This study employed a cross-sectional research design to investigate whether the stress that is associated with an HIV/AIDS diagnosis, which I refer to as HIV status stress, directly impacts adherence to HIV/AIDS treatment and prevention or whether the impact of stress on adherence occurs through the effect of HIV status stress on internal health locus of control. The possible mediation of internal health locus of control in the relationship between social support and adherence to HIV/AIDS treatment and prevention was also investigated. Finally, this study investigated the moderating role of social support in the relationship between HIV status stress and adherence to HIV/AIDS treatment and prevention.

##### **4.1. Study Sample**

The study sample was comprised of 212 respondents who were randomly selected from the membership of two Dar-es-Salaam-based AIDS Service Organizations (ASOs): WAMATA and SHDEPHA. A minimum sample size of 200 was established for the study. Power calculation using SPSS software (sample power) showed that given a significance level of .05 and a desired power of .80, a sample size of 126 would be required to detect an increment of .10 in the  $R^2$  when one study variable was added to a

set of six control variables. The selected sample size considerably exceeded the required sample size to allow for refusals and incomplete interviews.

Both organizations (i.e., SHDEPHA and WAMATA) agreed to participate in this research (Appendices C and D). Respondents were adult men and women over the age of 18 years, in relatively good health, and residing in the municipalities of Ilala or Kinondoni. The clinical staff at each agency developed a list of clients who met these selection criteria. Based on their clinical observation of clients during home care visits and support group meetings, the staff personnel were able to exclude from the list those clients who were too ill to participate in the interview.

I reviewed the list from each organization, checked for duplicated names and, before the sampling procedure began, made sure that the names were listed correctly and a name appeared only once on the master list. After this process 426 unduplicated names remained on the master list, out of the 541 names that originally composed it. These 426 names constituted the final sampling frame.

An initial letter from the WAMATA Executive Officer was sent introducing the study to clients, and it was followed up by my own recruitment letter to the 426 people on the master list (Appendix E). Prospective participants were told that they were to receive \$2.00 as a token of appreciation for their time. They were also asked to indicate whether they wanted to be interviewed in their own homes or some other place. From those expressing an interest in participating in the study a random sample was drawn.

Since most clients did not have postal addresses, a member of the home care team, who had served as a driver and counselor since 1992, and who knew where clients in both organizations lived, hand delivered the letters to the PLHAs who did not have

postal addresses, and subsequently hand delivered their responses to me. He later became valuable in directing the interviewers to the PLHA's homes where most of the interviews took place.

All the 426 clients who received the recruitment letters agreed to participate if selected. Systematic sampling with a random start was used to draw the study sample (Aday, 1996; Dillman, 1979; Rubbin & Babbie, 1997; Salant & Dillman, 1994). By picking every other name on the list, 216 participants were randomly selected. Of those, 212 were interviewed. Two of the remaining four died before the interview date, one was too ill, and the fourth had moved.

## **4.2. Instrumentation**

A standardized questionnaire, consisting of five main sections, was developed for use in this study. The complete English version of the questionnaire can be found in Appendix I.

### **4.2.1. HIV Status Stress Scale**

HIV status stress, the independent variable, was measured by the HIV Status Stress Scale, a 30-item scale that I developed. The scale covers some of the aspects included in the Coping and Stress Profile developed by Olson (1995). Olson's items cover personal, work, couple, family and home; time, health, employment, neighborhood, and community stressors. However, the HIV Status Stress Scale did not focus on personal, work, couple and family dimensions in the same way as Olson's Coping and Stress Profile did because of differences in the populations studied.

The response options for the items composing the HIV Status Stress Scale items were: (1) Never, (2) Rarely, (3) Sometimes, (4) Usually, and (5) Always. A Not

Applicable (NA) option was also provided. The scale was pre-tested with 32 PLHA's in Dar-es-Salaam and its reliability coefficient was .83. Therefore, according to the pretest results, the 30-item HSS Scale was appropriate for application in the actual study.

As implemented, the HIV Status Stress Scale involved 30 items. For the purposes of data reduction, two options were considered for assessing the structure of the scale. The initial approach considered a two factor solution (Appendix K). Although the items loading on the first factor made sense conceptually, the second factor was not interpretable. Therefore, a second approach was tested. I examined the items that loaded on the first, pre-rotated factor. Seventeen items (i.e., #1, #4, #5, #8, #10, #11, #12, #13, #16, #19, #20, #21, #24, #25, #26, #28, and #30) had factor loadings of .4 or greater (Appendix L). These items had a common theme and were used to construct the HSS Scale. The 17 items were summed and averaged to obtain the total HSS score. Thus the scale scores could range from 1 to 5, with higher scores indicating greater stress. The 17-item HIV Status Stress Scale had an alpha of .89.

#### **4.2.2. Health Locus of Control Scale**

Form C of the Multidimensional Health Locus of Control Scale (Wallston, Wallston, & DeVellis, 1978) was used to assess respondents' health-related locus of control. Form C includes items that distinguish the role of doctors from the role of others, so it was considered appropriate for measuring the locus of control of people with a diagnosis of HIV/AIDS. Form C is made up of 18 items scored on a six-point scale as follows: (1) Strongly Disagree, (2) Moderately Disagree, (3) Slightly Disagree, (4) Slightly Agree, (5) Moderately Agree, and (6) Strongly Agree.

Wallston et al. (1978) indicate that Form C of the MHLC contains the following subscales that are to be scored individually: Internal Health Locus of Control, Chance Health Locus of Control, Doctors Health Locus of Control, and Other People Health Locus of Control. These last two subscales (i.e., Doctors and Other People) can be summed to produce the Powerful Others Health Locus of Control subscale, which is used in other versions of the MHLC. Based on previous studies, the MHLC subscales have internal consistency coefficients (Cronbach alphas) in the .60-.75 range and test-retest stability coefficients ranging from .60-.70 (Wallston, 1993; Wallston, Stein, & Smith, 1993).

**4.2.2.1. Factor analysis.** Although factors analysis showed that six factors had eigenvalues greater than 1.00, examination of the scree plot suggested the presence of four factors. However, further analysis, using a four factor solution with varimax rotation (Appendix M), resulted in three meaningful factors that corresponded approximately to the Chance, Internal, and Doctors subscales. The other factor was composed of a mixture of items from the *a priori* subscales.

Thus, factor analysis of the MHLC on the current data failed to fully explicate the measure's proposed structure, although the Chance, Internal, and Doctor subscales were identifiable. Of these, only the Chance subscale, composed of four items (Appendix N), had an acceptable alpha reliability (.72).

To be consistent with the intention of representing internal health locus of control, the four items on the Chance subscale, i.e., #2 (As to my condition, what will be will be), #9 (Luck plays a big part in determining how my condition improves), #11 (Whatever improvement occurs with my condition is largely a matter of good fortune), and #16 (If I

am lucky my condition will get better), were reverse scored so that a higher score indicated less reliance of chance, or, in other words, a rejection of chance. However, it is important to note that rejection of chance is not the same as attributing control over one's health to oneself. Respondents who reject chance as the explanation for their health status may see the actions of doctors, family, friends, or even themselves as being the determining influence. Thus, while the measure of rejection of chance is not exactly the same as one for internal health locus of control, it is being treated as an imperfect proxy for that concept in this study.

#### **4.2.3. Sources of Social Support (SOSS) Scale (Informal and Formal)**

Social Support was the moderating variable in this study. The measure used to assess social support was a modified version of the Sources of Social Support Scale developed by Koeske and Koeske (1990, 2001). The original measure was an 8-item scale that tapped information on two dimensions of social support: practical support and emotional support. The modified measure of social support obtained information on three dimensions of support: practical support, emotional support, and informational support, which was added for this study.

The modified scale measured the amount of practical, emotional, and informational support perceived to come from such categories of people as family, friends, neighborhood solidarity groups, medical personnel, AIDS services organizations, traditional healers, and faith healers. Response options were: (1) None At All, (2) A Little, (3) A Fair Amount, (4) Quite A Bit, and (5) A Great Deal. A Not Applicable (NA) option was provided. Each of the three subscales had 18 items. Total scores for each



subscale were computed by summing scores on all items except those receiving NA responses and taking an average using the number of valid responses as the base.

Evidence for the reliability and construct validity of the original scale is based on data from over a dozen studies of mostly American, but also two Korean, samples (Koeske & Koeske, 2001). The modified scale was not factor analyzed because items on it were not assumed to be correlated with each other since an individual who receives a high degree of support from one source may receive little support from another source. Thus, contributions of specific sources to overall support were expected to vary across individuals.

The sources of social support were grouped into three categories: informal sources of social support (i.e. support from different categories of family members, friends, and neighbors), formal sources of social support (i.e. support from doctors, ASO clinical staff, and ASO members.), and "other" sources of social support (i.e. support from faith healers and traditional healers). Therefore, a total of six subscales were established based on the source of social support (i.e., formal vs. informal) and the type of support (i.e., practical, emotional, and informational support); subscales based on "other" sources of social support were dropped because of a paucity of valid data.

When correlations among subscales were examined, high correlations between subscales measuring the three types of support were found with respect to both formal and informal sources of support (Appendix O). For that reason, total scores for informal and formal sources of support were obtained by summing the items across the three types of support (i.e., emotional, practical, and informational). However, since many participants were not employed, the items pertaining to support from employers and

coworkers (i.e., #11 and #12) were frequently coded as "not applicable." Therefore, these items were not included. Informal subscale scores were computed for cases that had valid data on at least five out of 11 items; formal subscale scores were computed for cases that had valid data on at least two out of three items. Subscale scores ranged from 1 to 5.

### *Adherence*

Adherence to HIV/AIDS treatment and prevention was the dependent variable in this study. The measure for adherence to HIV/AIDS treatment and prevention was the newly developed Adherence Scale. This was a 23-item scale, with one question having different wording for male and female respondents. The questions were specific to HIV/AIDS treatment, HIV/AIDS prevention, and to the self-care strategies that were possible within the context of Tanzania. This original Adherence Scale was pre-tested with 32 PLHA's in Dar-es-Salaam, along with the other three scales (i.e., HLC Scale, HSS Scale, and SOSS Scale). Its pretest reliability coefficient was  $\alpha = .77$ . The Adherence Scale was scored on a five-point scale, with the following options: (1) Never, (2) Rarely, (3) Sometimes, (4) Usually, and (5) Always. A Not Applicable (NA) option was also provided.

Subsequent to data collection, two items were dropped from the original scale, one, #20, because of high missing values and the other, #16, because its wording was similar to that of another item. The remaining 21 items were subjected to factor analysis. Based on the scree plot a two factor solution was identified. Examination of the two factors did not reveal a common conceptual theme among the items that loaded on either factor.

Inspection of the 21 items suggested that they could be divided into two logical grouping: those that addressed sexual risk and those that captured adherence to general health promotion and treatment recommendations. Six of the 21 items were identified as measuring sexual risk and the remaining 15 were identified as measuring general adherence to HIV treatment and prevention.

The six items addressing sexual risk included item #7 (I use a condom whenever having sex), #12 (I have sex with more than one partner), #15 (I have a sex partner who has other sex partners), #17 (I have not reduced my number of sex partners), #22 (I discuss my HIV prevention strategies with my partner(s)), and #23 (I have breastfed/encouraged my wife/partner to breastfeed our baby despite HIV). Two of these items, #7 and #22, had to be reverse coded. Because the responses to the six items were not normally distributed, and many of the items had high missing values, a count procedure was applied (values 2-5). The resulting index was still skewed; therefore, the index was dichotomized (0-1 for low and 2-6 for high). This dichotomous variable served as the measure of Sexual Risk in the analyses.

The remaining 15 variables, i.e., #1, #2, #3, #4, #5, #6, #8, #9, #10, #11, #13, #14, #18, #19, and #21, that reflected adherence to general HIV treatment and prevention regimens were subjected to a reliability analysis and an alpha of .65 was observed. Eliminating two items, i.e., #11 and #21, raised the reliability coefficient to .68. A scale, named Adhere, based on the 13 items, was computed when at least six of the 13 items had valid data; items were summed and then averaged. Thus scores on the Adherence Scale range from 1 to 5.

#### **4.2.4. Demographic and Background Information**

In addition to the scales, the survey obtained data on demographic characteristics that were important in describing the sample. These demographic characteristics could also be used as control variables.

Apart from the actual demographics of gender, age, religion, marital status, education, employment, income, birthplace (as a reflection of ethnicity within Tanzania), number of children, and type of housing, there were items that targeted information specific to the health condition and experiences of PLHAs as persons directly impacted by HIV/AIDS. Such items included eliciting information on the participants' specific AIDS symptoms and, whether or not they were on anti-retroviral therapy or not.

Some of the items were scored as dichotomous variables with (0) No or (1) Yes responses, including question #15 (currently polygamous marriage), question #16 (past polygamous marriage), and question #17 (steady sex partner), question 18 (casual sex partner), question #20 (parental status), question #63 (drug use), and question #65 (sharing of drug injecting needles). In addition, each HIV/AIDS symptom listed in question #29 was coded, (0) No or (1) Yes, as was each of the HIV treatment options listed in question #49. Gender (question #2) was scored (1) Female and (2) Male.

Other nominal variables included: region of birth (question #4), which listed 22 regions of Tanzania (including Zanzibar and Pemba) and one category to represent regions outside of Tanzania. There were three questions dealing with various aspects of religion (#5, #6, and #7). Questions 5 and 6 obtained data about religious affiliation, and were coded: (1) Islam, (2) Catholic, (3) Lutheran, and (4) Other, while question 7, importance of religion, was coded (1) Not very important, (2) important, and (3) Very important.

Education (question #8) included ten categories, which were later reduced to three, i.e., (0) None, (1) Primary and under or, (2) Above Primary. Question 19 (HIV+ Sex Partner) had three response categories, i.e., (0) No, (1) Yes, and (2) Don't Know. The questions on living situation (question #23) and housing type (question #24) each had three response categories. Responses to question 23 included (1) Live alone, (2) Live with 1-3 others, or (3) Live with 4-16. The response options for question 24 were (1) Home owner, (2) Rented accommodation, and (3) Housed by other(s).

The items on general health status (question #68) and life satisfaction (question #69) had three categories each which were (1) Very Poor or Poor, (2) Satisfactory or (3) Good or Very Good. Three questions addressed employment. Questions (#10) obtained data about employment and was coded as (1) Employed, (2) Retired, or (3) Unemployed. Questions #11 was based on the assumption that being employed required working 40 hours per week; therefore its coding entailed two categories, (1) 40 hours, and (2) Not Applicable (NA). Question #12 was coded as (1) 0, and (2) Yes as a measure for being involved in the informal type of self-employment.

Monthly income (question #13) had four response categories, i.e., (1) 15.00 and under, (2) 15.01-35.00, (3) 35.01-55.00 or, (4) over 55.00 (4). Marital status (question #14) too had four response categories, i.e., (1) Married, (2) Single, (3) Divorced/Separated, or (4) Widowed.

Age (question #3) was recorded in years. Other continuous variables included: questions #2 (number of children), question #22 (children aged under 18 living at home), question #24 (household size), question #25 (dependants under 18 years), question #26 (when infected); question 27 (years since infection), question #28 (when tested), and question #63 (year started type of treatment). The two questions on ASO involvement

were categorical variables, but question #67 on when a participant first joined an ASO was continuous.

#### **4.2.5. Translation**

The instrument was translated into Kiswahili, the language spoken in Tanzania (Appendices J). The translation of the instrument started as soon as professional translators were identified at the Kiswahili Department, University of Dar-es-Salaam. After that initial translation, the questions were translated back to English by the same member of the Kiswahili Department and by me. Once translation was completed, the questionnaire was pilot-tested with a group of PLHAs in Dar-es-Salaam.

#### **4.2.6. Pre-testing**

The pre-testing of the instruments took place as soon as approval was obtained from the National Institute for Medical Research (NIMRI) (Appendix B). Approval from the University of Pittsburgh was obtained prior to my travel to Tanzania (Appendix A). Although the University of Pittsburgh did not require a consent form, the NIMRI did. The sample for pilot-testing was a convenience sample consisting of the clients who were attending support group meetings during the two weeks of the pretest study. I was given a list of the names of healthy adult PLHAs who were members of the support group.

Each person on that list was sent a recruitment letter introducing myself and the study and asking if he or she would agree to volunteer as a participant for the pre-test interview (Appendix F). Each of those who agreed signed the letter and returned it to me in a self-addressed envelope.

A minimum of 30 PLHAs was needed for the pre-testing of the questionnaire; 32 agreed to the pre-test and were interviewed by me or one of the three research assistants

at a venue of their choice. I was responsible for the processing and analysis of the pretest data. The research assistants participated in pretest data entry. Information gained from the pre-test was used to make modifications, such as adding the question on drug addiction to the questionnaire.

### **4.3. Data Collection**

After selecting 216 participants by the sampling method described earlier in this chapter, I scheduled an average of three interviews a day for each interviewer. The member of the agency's home care team who had delivered the recruitment letter helped in scheduling meetings with the PLHAs who could not be contacted by mail or telephone.

Data were collected through face-to-face in-home interviews using the Kiswahili version of questionnaire. A few clients chose not to be interviewed in their own homes. Two were interviewed inside a car and one was interviewed (by me) in a café.

Interviews did not start until a consent form (Appendix G) was read to the prospective respondent and then signed to indicate consent to be interviewed. As it turned out, people were used to signing consent forms, and this process went more smoothly than I had anticipated.

The consent form, cover letter, and other letters that went to prospective participants were translated into Kiswahili (Appendix H). The interviews took forty-five minutes to one hour. Data collection (including pre-testing) took four months to complete. As anticipated, the interview process started in August, 2003, and ended in November, 2003.

#### **4.3.1. Training of the Research Assistants**

Two social work interns (one male and one female) and one University of Dar-es-Salaam graduate (female) served as research assistants. I conducted one week of training for all three research assistants on the administration of the questionnaire. I also oriented them to the professional ethics of confidentiality before they conducted the pre-test interviews with me.

The training focused on interviewing skills and the interviewing process; it also addressed the ethical guidelines for this study. It also aimed at building a team that would conduct itself ethically and professionally during the fieldwork. Role-plays were used so as to make sure that the research assistants had uniform interviewing skills.

The research assistants were involved in the process beginning with the pilot testing phase of the study instruments. Working on the pre-test enabled the research assistants to become familiar with the research approach prior to the main study, to become familiar with the questionnaire, and to understand the procedure involved in the interviewing process.

#### **4.4. Protection of Human Subjects**

Research approval was obtained from the University of Pittsburgh (USA) and from the NIMRI in Tanzania (Appendices A and B). Although the study was not expected to cause physical or psychological harm to the respondents, the protocol included identification of a standby referral counselor if need arose. The names of interviewees have been kept confidential and the privacy of participants was respected. The interview files are kept by me.



The interviewers were trained and warned against regarding any of the variable scales used in the study as diagnostic instruments. Participation was completely voluntary. Interviewers included me and three assistants (1 male and 2 females) who were familiar with the participants' right to self-determination, confidentiality, and informed consent.

The respondents reserved the right to drop out of the study if they felt uncomfortable. This was explained to them in the recruitment letter (Appendix F) and also at the beginning of the interview. All respondents, including one who did not complete the interviews, were given \$2.00 as token appreciation for their time.

#### **4.5. Analytic Plan**

I was solely responsible for entering the final data into the computer. Completed questionnaires were examined to see whether the items were answered appropriately and whether there were any items left unanswered. The first step in data analysis involved screening the data to identify and correct out-of-range values and inappropriate codes.

Univariate analyses, including measures of central tendency, variability, skewness, and kurtosis, were conducted for all of the main variables. To check for the presence of outliers and for possible violations of the assumption of normality, histograms and box-and-whisker plots were examined. Factor analysis was utilized to examine the dimensionality of three of the measures (i.e. the Health Locus of Control Scale, which was applied to an African sample for the first time, and the HIV Status Stress Scale and the Adherence Scale, which were developed for this study).

Bivariate correlations were produced to test the relationship between selected demographic variables and the major study variables. Correlational analyses also were undertaken to establish the relationships among the five major study variables.

Linear and logistic regression analyses were used to test the hypothesized models. One analysis tested whether rejection of chance health locus of control mediated the relationship between HIV status stress and adherence to HIV/AIDS treatment and prevention (Adhere and Sexual Risk). Another tested whether rejection of chance health locus of control mediated the relationship between social support (Informal and Formal) and adherence to HIV/AIDS treatment and prevention (Adhere and Sexual Risk). Lastly, linear and logistic regression models were used to test whether social support (Informal and Formal) moderated the relationship between HIV status stress and adherence to HIV/AIDS treatment and prevention (Adhere and Sexual Risk). In these analyses, selected demographic variables were entered on the first step as control variable.

## **5. CHAPTER FIVE: STUDY RESULTS**

The findings of the study are discussed in this chapter, starting with a presentation of demographic and background characteristics of the study participants. This is followed by a description of participants' health status and their involvement with AIDS Service Organizations. Following this, the results of bivariate analyses of relationships between study variables and demographic and background characteristics, and among the study variables themselves are discussed. The chapter concludes with the analyses of the study hypotheses, which were assessed via linear and logistic regression.

### **5.1. Description of the Study Sample**

#### **5.1.1. Demographic and Background Characteristics**

The research sample was comprised of 212 adult women (77%) and men (23%). For the sample as a whole, the age range was 19 to 63 years (mean= 38.20, SD= 8.68).

Table 3 shows the distribution of participants across the regions of their birth districts. The participants' districts of birth are distributed throughout Tanzania, including Zanzibar and Pemba. The majority of the participants (89.2%) were raised in mainstream religions (i.e. Islam, Catholic, or Lutheran). At the time of the survey, however, almost a fifth (19.3%) of the PLHAs characterized their religion as "other," typically Pentecostal Churches or charismatic religions, as shown in Table 4. Nearly everybody in the sample (91%) thought religion was very important.

**Table 3 Distribution of Region of Birth in Tanzania**

Region	N	%
Arusha	2	.9
Coastal	9	4.2
Dar-es-Salaam	27	12.7
Dodoma	10	4.7
Iringa	10	4.7
Kagera	15	7.1
Kigoma	14	6.6
Kilimanjaro	12	5.7
Lindi	12	5.7
Mara	8	3.8
Mbeya	19	.9
Morogoro	16	7.5
Mtwara	3	1.4
Mwanza	12	5.7
Rukwa	8	3.8
Ruvuma	1	.5
Shinyanga	4	1.9
Singida	10	4.7
Tabora	5	2.4
Tanga	13	6.1
Zanzibar and Pemba	2	.9

**Table 4 Distribution of Religious Affiliation**

Religion	At Birth N (%)	Currently N (%)
Islam	75 (35.4)	73 (34.4)
Catholic	78 (36.8)	71 (33.5)
Lutheran	36 (17.0)	27 (12.7)
Other Religions	23 (10.8)	41 (19.3)

As for education, 7.5% reported no formal education and 35.5% had education above the primary school level (over 7 years of education). Approximately 43% of the participants reported their monthly income level as about \$1.00 or less per day; just 14% reported being formally employed. The majority of the respondents were not formally employed (3% retired and 83% unemployed), although it is likely that many of these individuals were informally earning an income in what is known in Tanzania as the informal sector. About a one fifth (20.7%) owned a home, 55.8% rented, and 23.3% lived in a home owned by friends, family members or relatives, often in large households. Less than a half (42.9%) of the respondents lived in households with three or fewer other people. The rest (55.8%) lived in households of four to sixteen other members (Table 5).

In terms of marital status (Table 6), 55.7% of the participants were widows, 16.5% were single, and 12.3% were divorced or separated. The rest (15.7%) were married at the time of the interview. Five percent were in a polygamous marriage at the

**Table 5 Distribution of Educational Attainment and Socioeconomic Characteristics**

Variable	Category	N	%
Education	None at all	16	7.5
	Primary (and under)	125	59.0
	Above primary (up to degree)	71	33.5
Employment	Employed	30	14.2
	Retired	6	2.8
	Unemployed	176	83.0
Monthly Income	USD 15.00 and under	22	10.4
	USD 15.01 to USD 35.00	68	32.1
	USD 35.01 to USD 55.00	73	34.4
	Over USD 55.00	49	23.1
Living Situation	Home owner	43	20.7
	Rented accommodation	116	55.8
	Housed by other(s)	49	23.6
Household Size	Live alone	13	6.1
	Live with 1-3 others	91	36.8
	Live with 4-16	118	57.1

time of interview and 20% had been in a polygamous marriage in the past. Just over a quarter (26.4%) of the participants reported having a steady sexual partner at the time of the interview and 16% reported having a casual sex partner at that time.

**Table 6 Distribution of Relationship Status Characteristics**

Variable	Category	N	%
Marital Status	Married	33	15.7
	Single	35	16.5
	Divorced/Separated	26	12.3
	Widowed	118	55.7
Currently Polygamous	No	202	95.3
	Yes	10	4.7
Past Polygamous	No	169	79.7
	Yes	43	20.3
Steady Partner	No	156	73.6
	Yes	56	26.4
Casual Sex partner	No	179	84.4
	Yes	33	15.6
HIV+ Sex Partner	No	44	20.8
	Yes	98	46.2
	Don't Know	67	31.6

The majority of the respondents (84.9%) were parents. Those who were parents had, on average, 3.54 (SD= .96) children and had an average of 1.72 (SD=1.13) children under the age of 18 years living with them at the time of interview (Table 7).

**Table 7 Descriptive Statistics for Parental Status Indicators**

	N	Min.	Max.	Mean	SD
Number of children	180	1	9	3.54	1.96
Children under 18 years living at home	180	0	5	1.72	1.13

Although drug use was identified as an issue during the pre-test and two questions were added to survey to elicit this information, reports of substance use were exceedingly rare among the study respondents. Only one respondent reported use of marijuana and/or cocaine and one other respondent reported sharing drug-injecting needles.

### **5.1.2. Health Status**

Table 8 presents a list of common symptoms of opportunistic infections associated with HIV/AIDS. Of these, only two, cryptococcus/meningitis and Kaposi's sarcoma (KS), were reported by less than 10% of the participants. The most common symptoms experienced were cough, fatigue, fever, loss of appetite, malaria, skin rash, and weight loss, which were reported by more than 50% of the PLHAs in the sample. Candidiasis/oral thrush, diarrhea, night sweats, and tuberculosis (TB) were reported by more than 40%. Abdominal pain and pneumonia were reported by 30%, while pain/burning when urinating and vomiting were reported by nearly 30%. Shingles, or



**Table 8 Distribution of HIV/AIDS Symptoms**

Symptom	N	%
Abdominal pain	82	38.7
Pain/Burning when urinating	61	28.8
Candidiasis/oral thrush	91	42.9
Cough	162	76.4
Cryptococcus/Meningitis	12	5.7
Diarrhea	86	40.6
Fatigue	167	78.8
Fever	152	71.7
Loss of appetite	124	58.5
Kaposi's sarcoma (KS)	7	3.3
Malaria	142	67.0
Night sweats	92	43.4
Pneumonia	70	33.0
Skin rash	107	50.5
Tuberculosis (TB)	90	42.5
Vomiting	55	25.9
Weight loss	141	66.5

herpes zoster, which has come to be known as “mkanda wa jeshi” in Kiswahili, was frequently mentioned although it was not on the symptoms list.

Despite the fact that 96.2% of the participants reported having symptoms of opportunistic infections, only four (1.9%) of the PLHAs in the sample reported being on antiretroviral (ARV) treatment at the time of interview. Of those four, one started ARV therapy in 1998, and the three others started in 2003, the year of interview. However, all but six participants were on some form of treatment other than formal biomedical

interventions. These other forms of treatment included traditional healing practices and palliative care of opportunistic infections, including tuberculosis.

Many of the participants were in relatively good health, with 50.5% reporting satisfactory health status and 28.3% reporting good or very good general health status. However, 21.2% reported that their health status was poor or very poor. In contrast to their self-reported health status, respondents displayed less satisfaction with their lives generally. Fully 38% reported poor or very poor life satisfaction compared to 55% who reported a satisfactory life and 5.7% who reported good or very good life satisfaction (Table 9).

**Table 9 Distribution of Self-Reported Health Status and Life Satisfaction**

Variable	Category	N	%
General Health Status	Very Poor or Poor	45	21.2
	Satisfactory	107	50.5
	Good or Very Good	60	28.3
Life Satisfaction in General	Very Poor or Poor	82	38.7
	Satisfactory	118	55.7
	Good or Very Good	12	5.7

Respondents reported that an average of 7.48 years (SD= 3.82) had elapsed since becoming infected with HIV. Respondents estimated that they were tested for HIV an average of 2.43 years after being infected (Table 10). Only 44 (20.8%) participants reported being tested in the year they were infected.

**Table 10 Descriptive Statistics for Time Since Infection and between Infection and Testing**

	N	Min.	Max.	Mean	SD
Years since infected	212	0	19	7.48	3.82
Years between infection and testing	212	0	16	2.43	2.51

**5.1.3. Involvement with AIDS Service Organizations**

As for AIDS Service Organization (ASO) involvement, 13.2% of the respondents joined ASOs between 1990 and 1995, 42.5% joined during the 1996 to 1999 period, and 44.3% joined between 2000 and 2003, the year this study was conducted. Six (2.8%) of the participants reported joining a service agency before HIV testing, but the majority of the PLHAs (63.7%) reported becoming an ASO member in the year in which they were tested for HIV. The remaining 33.5% joined one or more years after testing. Although 21.3 % of the participants reported membership in four or five ASOs, the majority belonged to fewer ASOs. For example, 60.2% belonged to two or three agencies, and 18.5% restricted themselves to only one agency (Table 11).

**Table 11 Distribution of ASO Involvement Indicators**

Variable	Category	N	%
How many ASOs	1	39	18.5
	2-3	127	60.2
	4-5	45	21.3
When first joined ASO	1990-1995	28	13.2
	1996-1999	90	42.5
	2000-2003	94	44.3
Years between testing and joining ASO	Joined ASO before testing	6	2.8
	Joined same year as testing	135	63.7
	Joined 1-3 years after testing	56	26.4
	Joined 4 or more years after testing	15	7.1

## 5.2. Descriptive Analyses of Study Variables

### 5.2.1. Univariate Statistics

The descriptive statistics for the study's analytic variables are discussed in this section. HIV status stress (HSS), the independent variable, is discussed first. The sources of social support (SOSS) measures are then presented. These are followed by a description of the rejection of chance health locus of control. Finally, the measures for adherence (Adhere and Sexual Risk) are discussed.

**5.2.1.2. HIV status stress (HSS) Scale.** As explained in Chapter 4, out of the original 30 items, 17 were retained in the revised version of the scale. The HIV Status Stress (HSS) Scale had a mean of 2.62 (median= 2.53, SD= .80), representing an average rating between (2) Rarely and (3) Sometimes. With a low degree of positive skewness (.46), the distribution was approximately normal.

**5.2.1.3. Sources of social support (Total Informal and Total Formal).** On the average, respondents perceived receiving more support from formal sources (mean=3.91, median=3.11, SD=0.79) than from informal sources (mean=3.02, median=3.01, SD= 0.72). The informal social support scale was approximately normally distributed (skewness=.124), whereas the formal social support scale was highly skewed to the left (skewness = -1.124). Therefore, a square transformation was applied to the total formal scale; this reduced the skewness to -.650.

**5.2.1.4. The health locus of control scale.** Unlike the three other scales, the health locus of control (HLC) scale did not have any missing values. All 212 participants responded to all 18 items on the HLC Scale.

As described in Chapter 4, after factor analysis, rejection of chance emerged as the most appropriate scale to represent internal health locus of control in subsequent analyses. The four-item scale had a mean of 3.24 (median= 3.25, SD= 1.90). A mean of 3.24 suggests that respondents, on average, rejected chance to a moderate degree. The distribution was approximately normal (skewness = .138).

**5.2.1.5. Adhere and sexual risk scales.** As described in Chapter 4, the original Adherence Scale was divided into two scales: Adhere and Sexual Risk. The Adhere Scale was created by summing the responses to the 13 constituent items and then taking the average. Thus, scores on the Adhere Scale could range from 1 to 5, with higher scores indicating greater adherence to general HIV/AIDS treatment and prevention activities. The mean was 3.57 (median= 3.61, SD= .52), which was higher than the middle scale value of 3, labeled as “Sometimes”. Skewness was -.04 and the distribution was approximately normal.

The Sexual Risk indicator was created by counting the number of responses with values of 2 or higher (on a scale of 1 to 5) among the 6 constituent items (Recall that a response value

of 2 is associated with the label “Rarely.”). The Sexual Risk indicator was subsequently transformed into a dichotomous variable. The dichotomized Sexual Risk variable categorized respondents into two groups: those reporting low sexual risk, i.e., no more than one sexual risk behavior (44.8%), and those indicating higher sexual risk, i.e., engagement in two or more sexual risk behaviors associated with HIV transmission (55.2%).

### 5.3. Bivariate Analyses

*Relationship of demographic/background variables to study variables.* The correlation between selected major demographic variables (age, gender, education, income, marital status, and parental status) and each of the main study variables, HIV Status Stress, Social Support (Informal and Formal), Rejection of Chance, and Adherence (Adhere and Sexual Risk), are displayed in Table 12. Selection of the six demographic and background variables was based on *a priori* knowledge about their importance both to the general Tanzanian population and Tanzanian PLHAs.

As shown in Table 12, HIV Status Stress was not significantly correlated with any of the demographic characteristics. Informal social support was negatively correlated with being separated/divorced, meaning that participants who were separated or divorced perceived having less informal support than participants who were married, single, or widowed. Informal social support also was negatively correlated with parental status; thus, those who had children perceived having less informal social support than those without children. Formal social support was positively correlated with monthly income,

**Table 12 Correlation of Demographic Characteristics and Study Variables**

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	HIV Status Stress Scale	Informal Social Support	Formal Social Support	Rejection of Chance HLC Scale	Adhere Scale	Sexual Risk
Gender <sup>a</sup>	-.07	.04	-.01	.20*	.05	.08
Age in years	-.07	.05	.09	.11	.12	-.19**
Education <sup>b</sup>	-.06	-.01	.00	.01	.00	.12
Monthly Income	-.13	.11	.14*	.35***	.22**	-.09
Married <sup>c</sup>	.04	.11	-.09	-.05	-.02	.18**
Single <sup>c</sup>	-.10	.05	.06	.02	-.01	.07
Separated/Divorced <sup>c</sup>	-.11	-.17*	-.02	.11	.08	.02
Parental status <sup>c</sup>	.04	-.13*	-.06	.03	.04	-.03

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<sup>a</sup> 1=Female, 2=Male

<sup>b</sup> 1=Primary or less; 2=More than primary education

<sup>c</sup> 0=No, 1=Yes

\*p<.05, \*\*p<.01, \*\*\*p<.001

indicating that participants with higher incomes tended to perceive having a greater degree of formal support than participants with lower incomes.

The Rejection of Chance HLC was positively correlated with both gender and monthly income. Males tended to reject chance more than female participants, and participants with higher incomes tended to reject chance to a greater degree than participants with lower incomes. The Adhere Scale was correlated with only one demographic variable, monthly income: participants with higher incomes tended to report adhering to HIV/AIDS treatment and prevention more than participants with lower incomes. Sexual risk was negatively correlated with age, indicating that younger participants were more likely to be at a higher level of sexual risk than older participants. Sexual risk was also positively correlated with being married,

indicating that married participants were more likely to be at a higher level of sexual risk than participants who were not currently married.

**5.3.1. Relationship among study variables.** The bivariate correlations between study variables are presented in Table 13. There was a significant negative correlation between HIV Status Stress Scale and the Adhere Scale ( $r = -.58$ ,  $p < .001$ ) and a significant positive correlation between HIV Status Stress and Sexual Risk ( $r = .16$ ,  $p < .05$ ). This suggests that as HIV status stress increases adherence to HIV/AIDS treatment and prevention activities decline. In addition, as HIV status stress rises so too does sexual risk. No other study variable was significantly correlated with either outcome variable.

There was a low but positive correlation between formal social support and the Rejection of Chance HLC ( $r = .14$ ,  $p < .05$ ), such that those who perceived having more formal social support were also likely to reject chance as the explanation for their health situation. There was a significant positive correlation between total informal and formal support ( $r = .58$ ,  $p < .001$ ). Finally, there was a significant negative correlation between Adhere and Sexual Risk, the two dependent variables ( $r = -.32$ ,  $p < .001$ ). This suggests that increased adherence to general HIV/AIDS treatment and prevention activities is associated with a lower level of sexual risk.



**Table 13 Bivariate Correlations among Study Variables**

	HIV Status Stress Scale	Total Informal Social Support	Square Transform of Formal Social Support	Rejection of Chance HLC Scale	Adhere Scale
HIV Status Stress Scale					
Total Informal Social Support	.04				
Square Transformation of Formal Social Support	-.02	.58**			
Rejection of Chance HLC Scale	.00	-.02	.14*		
Adhere Scale	-.58**	.04	.08	.05	
Sex Risk (dichotomous)	.16*	.10	.05	.04	-.32**

\*p < .05, \*\*p < .01, \*\*\*p<.001

#### **5.4. Testing the Study's Hypotheses**

Regression analyses tested the hypothesized mediation and moderation models involving HIV status stress, Informal social support and Formal social support (FMLSUPP), Rejection of Chance HLC, and Adherence (Adhere and Sexual Risk). Hypothesis testing was done through linear regression for all the variables except sexual risk, which was dichotomized and, therefore, required using logistic regression.

The six demographic control variables (i.e., sex, age, education, monthly income, marital status, and parental status) were entered on the first step in each analysis. Age and monthly income were treated as score variables. The other four demographic variables were treated as dichotomous dummy variables. For the marital status variable the “widowed” category was omitted so as not to overdetermine the regression models.

##### **5.4.1. Hypothesis 1**

Hypothesis 1a: There is a direct relationship between HIV status stress (HSS) and Adherence to HIV treatment and prevention (Adhere and Sexual Risk)

Table 14 shows the results of a linear regression with HIV Status Stress as the predictor and Adhere as the dependent variable. As the table shows, when the demographic variables were entered on the first step, monthly income was a statistically significant predictor; higher income was associated with greater adherence. After HIV Status Stress was entered on the second step, monthly income remained significant, although its effect diminished. The coefficient for HIV Status Stress was negative and statistically significant ( $B = -.36$ ,  $p < .001$ ). This means that as HIV Status Stress increases, Adhere decreases. The complete set of predictors explained 35% of the variance in Adhere.

**Table 14 Linear Regression of HIV Status Stress (HSS) on Adhere**

	Step 1		Step 2	
	B	$\beta$	B	$\beta$
(Constant)	3.09***	-	4.37***	-
Gender <sup>a</sup>	-.03	-.02	-.04	-.04
Age in years	.004	.07	-.001	-.01
Education <sup>b</sup>	-.01	-.01	-.03	-.03
Monthly Income	.11*	.20*	.08*	.15*
Married <sup>c</sup>	.02	.01	.01	.01
Single <sup>c</sup>	.07	.05	-.06	-.05
Separated/Divorced <sup>c</sup>	.14	.09	.03	.02
Parental status <sup>c</sup>	.06	.04	.05	.03
HSS Scale	-	-	-.36***	-.56***

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes  
 $R^2 = .05$  for Step 1 ( $p > .05$ );  $\Delta R^2 = .300$  for Step 2 ( $p < .001$ ).

\* $p < .05$ ,  $p < .01$ , \*\*\* $p < .001$

Table 15 shows the results of a logistic regression with HIV Status Stress as a predictor of Sexual Risk. As seen in Table 15, when the demographic variables were entered on step 1, the only significant effect was for the marital status of “married.” The odds ratio was 3.07, which indicates that the odds of falling into the higher level of sexual risk behaviors are approximately three times greater for married participants than for those participants not currently married. The results of step 2 show that the dummy variable “married” remained significant. HIV Status Stress was a significant predictor of Sexual Risk. The odds ratio was 1.58. This indicates that higher levels of stress are associated with greater odds of falling into the higher level of sexual risk.

**Table 15 Logistic Regression of HIV status stress (HSS) on Sexual Risk**

	Step 1		Step 2	
	B	Exp(B)	B	Exp(B)
Constant	.26	1.30	-1.32	.27
Gender <sup>a</sup>	.53	1.69	.54	1.72
Age in years	-.04	.96	-.04	.97
Education (dichotomous) <sup>b</sup>	.55	1.74	.60	1.82
Monthly Income	-.24	.79	-.22	.80
Married <sup>c</sup>	1.12*	3.08*	1.18*	3.24*
Single <sup>c</sup>	.46	1.59	.66	1.95
Separated/Divorced <sup>c</sup>	.24	1.27	.38	1.47
Parental status <sup>c</sup>	.60	1.83	.63	1.87
HIV Status Stress Scale	-	-	.46*	1.58*

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes

For step 1 model chi-square=20.624,  $p < .01$ ; for step 2 chi-square increase=5.893,  $p < .01$ . \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .0001$

Based on the analyses presented in Tables 14 and 15, Hypothesis 1a is supported.

Hypothesis 1b: There is a direct relationship between HIV Status Stress and rejection of chance health locus of control.

Table 16 shows results of a linear regression of HIV Status Stress on rejection of chance health locus of control HLC. Again, income proved to be the only demographic characteristic predicting the dependent variable. This was true for both step 1, when just the demographic variables were entered, and step 2, when the HIV Status Stress score was added to the model. The coefficient for HIV Status Stress, entered on step 2, was not statistically significant ( $B=.10$ ,  $p>.05$ ). Therefore, hypothesis 1b was not supported.

**Table 16 Linear Regression of HIV status stress (HSS) or Rejection of Chance Health Locus of Control (HLCRCH)**

	Step 1		Step 2	
	B	$\beta$	B	$\beta$
(Constant)	1.45*	-	1.11	-
Gender <sup>a</sup>	.30	.11	.30	.11
Age in years	.003	.02	.005	.03
Education <sup>b</sup>	.03	.01	.03	.01
Monthly Income	.40***	.31***	.40***	.31***
Married <sup>c</sup>	-.15	-.05	-.15	-.05
Single <sup>c</sup>	.09	.03	.13	.04
Separated/Divorced <sup>c</sup>	.30	.08	.33	.09
Parental status <sup>c</sup>	.21	.06	.21	.06
HIV Status Stress Scale	-	-	.10	.06

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes  
 $R^2 = .14$  for Step 1 ( $p < .001$ );  $\Delta R^2 = .004$  for Step 2 (ns).

\* $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Hypothesis 1c: Rejection of Chance health locus of control (HLCRCH) mediates the relationship between HIV status stress (HSS) and adherence (Adhere and Sexual Risk).

In testing Hypothesis 1a HIV Status Stress was found to have a direct, inverse effect on Adhere (Table 14). HIV Status Stress also had a direct influence on Sexual Risk (Table 15). However, in testing Hypothesis 1b, HIV Status Stress, the independent variable, did not predict the rejection of chance locus of control, the mediator ( $B = .10$ ,  $p > .05$ ). A necessary condition for mediation is that the independent variable has a significant relationship to the mediator variable (Baron & Kenny, 1986). Therefore, hypothesis 1c cannot be supported.

#### **5.4.2. Hypothesis 2**

Hypothesis 2a: There is a direct relationship between social support (Informal and Formal) and adherence (Adhere and Sexual Risk).

Hypothesis 2a was tested separately for Informal and Formal support. The results of linear regression analyses with Informal and Formal social support, respectively, as predictors of adherence are presented in Tables 17 and 18. As these Tables illustrate, neither Informal ( $B=.01$ ,  $p>.05$ ) nor Formal ( $B=.00$ ,  $p>.05$ ) social support was a significant predictor of Adhere after controlling for the demographic variables. Therefore, Hypothesis 2a was not supported when Adhere was the dependent variable.

**Table 17 Linear Regression of Informal Social Support on Adhere**

	Step 1		Step 2	
	B	$\beta$	B	$\beta$
(Constant)	3.06**	-	2.99	-
Gender <sup>a</sup>	-.04	-.03	-.04	-.03
Age in years	.005	.09	.005	.08
Education <sup>b</sup>	-.02	-.02	-.02	-.02
Monthly Income	.11**	.21**	.11**	.20**
Married <sup>c</sup>	.02	.01	.01	.01
Single <sup>c</sup>	.07	.05	.07	.05
Separated/Divorced <sup>c</sup>	.14	.09	.15	.09
Parental status <sup>c</sup>	.05	.04	.06	.04
Informal Social Support	-	-	.009	.04

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes  
 $R^2 = .06$  for Step 1 ( $p > .05$ );  $\Delta R^2 = .001$  for Step 2 ( $p > .05$ ).

\* $p<.05$ , \*\* $p<.01$ , \*\*\* $p<.001$

**Table 18 Linear Regression of Formal Social Support on Adhere**

	Step 1		Step 2	
	B	$\beta$	B	$\beta$
(Constant)	3.06***	-	3.01***	-
Gender <sup>a</sup>	-.04	-.03	-.03	-.03
Age in years	.005	.09	.005	.08
Education <sup>b</sup>	-.02	-.02	-.02	-.02
Monthly Income	.11**	.21**	.11**	.20**
Married <sup>c</sup>	.02	.01	.02	.02
Single <sup>c</sup>	.07	.05	.07	.05
Separated/Divorced <sup>c</sup>	.14	.09	.18	.09
Parental status <sup>c</sup>	.05	.04	.06	.04
Formal Social Support	-		.000	.04

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=no, 1=yes  
 $R^2 = .06$  for Step 1 ( $p > .05$ );  $\Delta R^2 = .002$  for Step 2 ( $p > .05$ ).  
 \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

The results of logistic regression analyses with Informal and Formal social support, respectively, as predictors of Sexual Risk are presented in Tables 19 and 20. As these tables illustrate, neither Informal social support ( $B=.14$ ,  $\text{Exp}(B)=1.15$ ,  $p>.05$ ) nor Formal social support ( $B=.005$ ,  $\text{Exp}(B)=1.005$ ,  $p>.05$ ) was a significant predictor of Sexual Risk after controlling for the demographic variables. Therefore, Hypothesis 2a also was not supported when Sexual Risk was the dependent variable.

**Table 19 Logistic Regression of Informal Social Support on Sexual Risk**

	Step 1		Step 2	
	B	Exp(B)	B	Exp(B)
Constant	.29	1.34	-.85	.43
Gender <sup>a</sup>	.54	1.72	.55	1.73
Age in years	-.04*	.96*	-.05*	.96*
Education <sup>b</sup>	.56	1.76	.56	1.75
Monthly Income	-.25	.78	-.28	.76
Married <sup>c</sup>	1.13*	3.08*	1.11*	3.03*
Single <sup>c</sup>	.48	1.58	.49	1.64
Separated/Divorced <sup>c</sup>	.24	1.27	.40	1.49
Parental status <sup>c</sup>	.61	1.84	.78	2.17
Informal Social Support	-	-	.14	1.15

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes

Note: For step 1 model chi-square=21.789,  $p < .01$ ; for step 2 chi-square increase=3.61,  $p < .10$ .

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



**Table 20 Logistic Regression of Formal Social Support on Sexual Risk**

	Step 1		Step 2	
	B	Exp(B)	B.	Exp(B)
Constant	.29	1.34	-.29	.75
Gender <sup>a</sup>	.54	1.72	.59	1.80
Age in years	-.04*	.96*	-.04*	.96*
Education Dichotomous <sup>b</sup>	.56	1.76	.57	1.77
Monthly Income	-.25	.78	-.28*	.75
Married <sup>c</sup>	1.13*	3.08*	1.19*	3.29*
Single <sup>c</sup>	.46	1.58	.45	1.57
Separated/Divorced <sup>c</sup>	.24	1.27	.26	1.30
Parental status <sup>c</sup>	.61	1.84	.69	1.99
Formal Social Support	-	-	.005	1.01

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes

Note:  $R^2 = .06$  for Step 1 ( $p > .05$ );  $\Delta R^2 = .002$  for Step 2 ( $p > .05$ ).

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Hypothesis 2b: There is a direct positive relationship between social support (Informal and Formal) and Rejection of chance health locus of control (HLCRCH)

Tables 21 and 22 show the results of regression models with Informal and Formal social support, respectively, as predictors of rejection of chance health locus of control. As these tables display, neither Informal social support ( $B = -.02$ ,  $p > .05$ ) nor Formal social support ( $B = .002$ ,  $p > .05$ ) was a significant predictor of Adhere after controlling for the demographic variables. Therefore, Hypothesis 2b was not supported.

**Table 21 Linear Regression of Informal Social Support on Rejection of Chance Health Locus of Control (HLCRCH)**

	Step 1		Step 2	
	B	$\beta$	B	$\beta$
Constant	1.42*	-	1.62*	-
Gender <sup>a</sup>	.28	.10	.28	.10
Age in years	.005	.03	.005	.04
Education <sup>b</sup>	.02	.01	.02	.01
Monthly Income	.40***	.31***	.40***	.31***
Married <sup>c</sup>	-.15	-.05	-.14	-.04
Single <sup>c</sup>	.10	.03	.09	.03
Separated/Divorced <sup>c</sup>	.30	.08	.27	.07
Parental status <sup>c</sup>	.20	.06	.18	.05
Informal Social Support	-	-	-.02	-.04

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes  
 $R^2 = .15$  for Step 1 ( $p < .001$ );  $\Delta R^2 = .002$  for Step 2 ( $p > .05$ ).

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table 22 Linear Regression of Formal Social Support on Rejection of Chance Health Locus of Control**

	Step 1		Step 2	
	B	$\beta$	B	$\beta$
(Constant)	1.42*	-	1.12*	-
Gender <sup>a</sup>	.28	.10	.30	.11
Age in years	.005	.03	.003	.02
Education <sup>b</sup>	.02	.01	.02	.01
Monthly income	.40***	.31***	.38***	.30***
Married <sup>c</sup>	-.15	-.05	-.13	-.04
Single <sup>c</sup>	.10	.03	.08	.03
Separated/Divorced <sup>c</sup>	.30	.08	.31	.09
Parental status <sup>c</sup>	.20	.06	.24	.07
Formal Social Support	-	-	.002	.10

a 1=Female, 2=Male; b 1=None or primary 2=More than primary; c 0=No, 1=Yes  
 $R^2 = .15$  for Step 1 ( $p < .001$ );  $\Delta R^2 = .002$  for Step 2 ( $p > .05$ ).

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Hypothesis 2c: Rejection of chance health locus of control (HLCRCH) mediates the relationship between social support (Informal and Formal) and adherence (Adhere and Sexual Risk).

In testing Hypothesis 2a, neither Informal nor Formal social support was found to be a significant predictor of Adhere after controlling for the selected demographic variables (Tables 17 and 18). Similarly, neither Informal nor Formal social support was found to be a significant predictor of Sexual Risk after controlling for the demographic variables (Tables 19 and 20). In testing Hypothesis 2b, it was found that neither Informal nor Formal social support significantly predicted Rejection of Chance HLC after controlling for the demographic variables (Tables 21 and 22).

Two of the necessary conditions for mediation are: first, that the independent variable must be related to the dependent variable; and, second, that the independent variable must be related to the mediator (Baron & Kenny, 1986). Since neither the first nor the second condition was met, Hypothesis 2c can not be supported.

### **5.4.3. Hypothesis 3**

Hypothesis 3: Social support (Informal and Formal) buffers the relationship between HIV Status Stress (HSS) and Adherence (Adhere and Sexual Risk).

The moderating role of social support was tested through a three-step linear regression model in the case of Adhere and a three-step logistic regression model in the case of Sexual Risk. In each model, the selected demographic variables were entered on the first step. The independent variable (HIV Status Stress) and the moderator variable (Social Support) were entered as predictors on the second step. Finally, the product of the independent and moderator variables was entered on the third step to represent the interaction effect.

Table 23 shows the results of the linear regression model testing the moderating role of Informal social support in the relationship between HIV Status Stress and Adhere. Table 24 shows the same for the moderating role of Formal social support.

**Table 23 Linear Regression Testing the Moderating Effect of Informal Social Support in the Relationship between HIV Status Stress (HSS) and Adhere**

	Step 1		Step 2		Step 3	
	B	$\beta$	B	$\beta$	B	$\beta$
(Constant)	3.09***	-	4.32***	-	4.58***	-
Gender <sup>a</sup>	-.03	-.02	-.04	-.04	-.05	-.04
Age in years	.004	.07	-.001	-.02	-.002	-.03
Education <sup>b</sup>	-.01	-.01	-.03	-.03	-.03	-.03
Monthly Income	.11*	.20*	.08*	.14*	.08*	.14*
Married <sup>c</sup>	.02	.01	.002	.001	-.003	-.002
Single <sup>c</sup>	.08	.05	-.06	-.05	-.07	-.05
Separated/Divorced <sup>c</sup>	.14	.09	.05	.03	.04	.03
Parental status <sup>c</sup>	.06	.04	.07	.05	.06	.04
HSS Scale	-	-	-.36***	-.57***	-.48***	-.75***
Informal Social Support	-	-	.02	.08	-.08	-.07
Product Term (HIV Status Stress * Informal Social Support)	-	-	-	-	.01	.25

a 1=female, 2=male; b 1=none or primary 2=more than primary; c 0=no, 1=yes

$R^2 = .054$  for Step 1 ( $p > .05$ );  $\Delta R^2 = .305$  for Step 2 ( $p < .001$ );  $\Delta R^2 = .002$  for Step 3 ( $p > .05$ )

\* $p < .05$ , \*\* $p < .01$  \*\*\* $p < .001$

**Table 24 Linear Regression Testing the Moderating Effect of Formal Social Support in the Relationship between HIV status stress (HSS) and Adhere**

	Step 1		Step 2		Step 3	
	B	$\beta$	B	$\beta$	B	$\beta$
(Constant)	3.09***	-	4.32***	-	4.72***	-
Gender <sup>a</sup>	-.03	-.02	-.04	-.03	-.03	-.02
Age in years	.004	.07	-.001	-.02	-.002	-.03
Education <sup>b</sup>	-.01	-.01	-.03	-.03	-.02	-.02
Monthly Income	.11*	.20*	.08*	.14*	.08*	.14*
Married <sup>c</sup>	.02	.01	.002	.01	-.003	.01
Single <sup>c</sup>	.08	.05	-.06	-.05	-.08	-.06
Separated/Divorced <sup>c</sup>	.14	.09	.05	.02	.02	.01
Parental status <sup>c</sup>	.06	.04	.07	.04	.05	.04
HSS Scale	-	-	-.36***	-.56***	-.50***	-.78***
Formal Social Support	-	-	.02	.05	-.002	-.23
Product Term (HIV Status Stress * Formal Social Support)	-	-	-	-	.01	.35

a 1=female, 2=male; b 1=none or primary 2=more than primary; c 0=no, 1=yes

$R^2 = .054$  for Step 1 ( $p > .05$ );  $\Delta R^2 = .301$  for Step 2 ( $p < .001$ );  $\Delta R^2 = .006$  for Step 2 ( $p > .05$ )

\* $p < .05$ , \*\* $p < .01$  \*\*\* $p < .001$

As shown in Table 23, the coefficient for the product term of Informal support and HIV Status Stress was not significant ( $B=.01$ ,  $p > .05$ ). Similarly, as shown in Table 24, the coefficient for the product term of Formal support and HIV Status Stress was not significant ( $Beta=.001$ ,  $p > .05$ ). Therefore, the moderating role of Social Support (Informal and Formal) with respect to Adhere was not supported.

Tables 25 and 26 show the results of logistic regression models that tested the moderating role of Informal and Formal social support in the relationship between HIV Status Stress and Sexual Risk. As seen in Table 25, the coefficient for the product of Informal social support and HSS was significant ( $B=-.193$ ,  $Exp(B)=.824$ ,  $p<.05$ ). However, as seen in Table 26, the coefficient for the product of Formal social support and HSS was not significant ( $B=-.007$ ,  $Exp(B)=.993$ ,  $p>.05$ ). Thus, the moderating role of Informal social support in the relationship between HIV Status Stress and Sexual Risk was supported, but the moderating role of Formal social support was not supported.

**Table 25 Logistic Regression testing of the Moderating Effect of Informal Social Support in the Relationship between HIV Status Stress and Sexual Risk**

	Step 1		Step 2		Step 3	
	B	Exp(B)	B	Exp(B)	B	Exp(B)
Constant	.26	1.30	-2.36	.10	-7.45*	.001*
Gender <sup>a</sup>	.53	1.69	.55	1.73	.64	1.89*
Age	-.04	.96	-.04	.96	-.04	.96
Education <sup>b</sup>	.55	1.74	.60	1.81	.61	1.84
Monthly income	-.24	.79	-.25	.78	-.26	.77
Married <sup>c</sup>	1.12*	3.08*	1.17*	3.21*	1.27*	3.57*
Single <sup>c</sup>	.46	1.59	.69	1.99	.77	2.17
Separated/Divorced <sup>c</sup>	.24	1.27	.54	1.72	.67	1.96
Parental status <sup>c</sup>	.60	1.83	.77	2.17	.94	2.57
HIV Status Stress	-	-	.45*	1.57*	2.21*	9.09*
Informal Social Support	-	-	.13	1.14	.64*	1.90*
Product term (HIV Status Stress * Informal Social Support)	-	-	-	-	-.19*	.82*

a 1=female, 2=male; b 1=none or primary 2=more than primary; c 0=no, 1=yes

For step 1 model chi-square=20.62,  $p < .01$ ; for step 2 chi-square increase=9.05,  $p < .05$ ; for step 3 chi-square increase= 4.353,  $p < .05$ .

\* $p < .05$ , \*\* $p < .01$  \*\*\* $p < .001$



**Table 26 Logistic Regression testing of the Moderating Effect of Formal Social Support in the Relationship between HIV Status Stress and Sexual Risk**

	Step 1		Step 2		Step 3	
	B	Exp(B)	B	Exp(B)	B	Exp(B)
Constant	.26	1.30	-1.93	.15	-4.81**	.01
Gender <sup>a</sup>	.53	1.69	.58	1.79	.50	1.65
Age	-.04	.96	-.04	.96	-.03	.97
Education <sup>b</sup>	.55	1.74	.61	1.84	.59	1.81
Income	-.24	.79	-.25	.78	-.27	.77
Married <sup>c</sup>	1.12*	3.08*	1.27*	3.48*	1.31**	3.72**
Single <sup>c</sup>	.46	1.59	.67	1.95	.74	2.10
Separated/ Divorced <sup>c</sup>	.24	1.27	.42	1.52	.51	1.67
Parental status <sup>c</sup>	.60	1.83	.70	2.02	.75	2.11
HIV Status Stress	-	-	.46*	1.59*	1.46*	4.29*
Formal Social Support	-	-	.005	1.01	.02*	1.03*
Product term (HIV Status Stress * Formal Social Support)	-	-	-	-	-.007	.99

a 1=female, 2=male; b 1=none or primary 2=more than primary; c 0=no, 1=yes

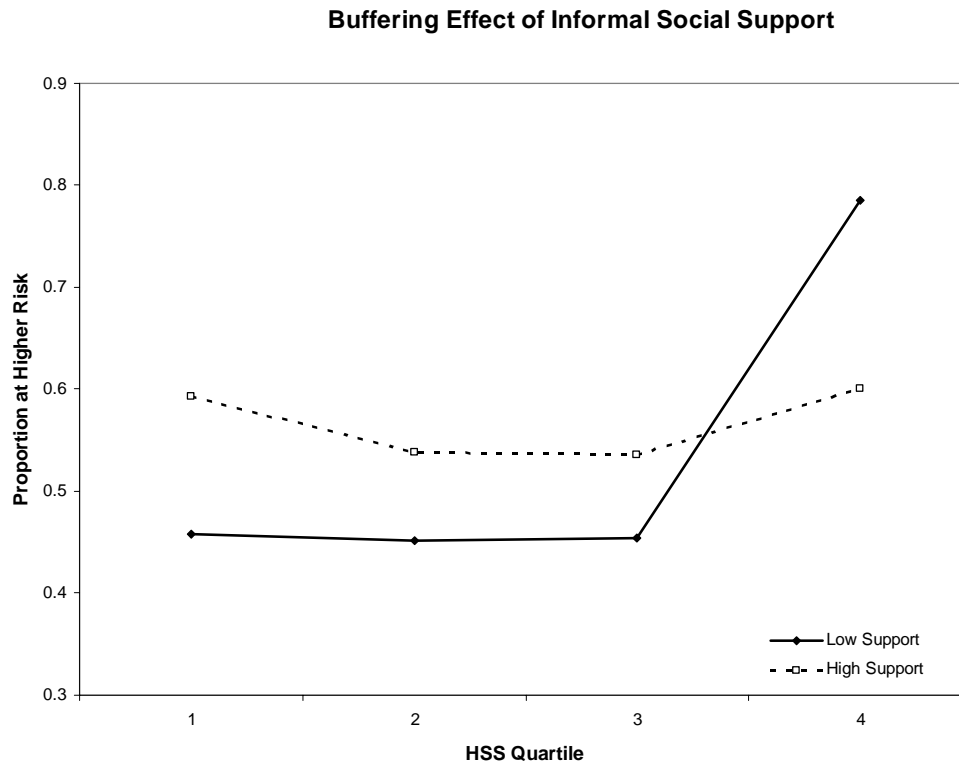
For step 1 model chi-square=20.62,  $p < .01$ ; for step 2 chi-square increase=8.42,  $p < .05$ ; for step 3 chi-square increase= 3.112,  $p > .05$ .

\* $p < .05$ , \*\* $p < .01$  \*\*\* $p < .001$

**5.4.3.1. Subgroup Analysis.** Subgroup analysis was performed to investigate the nature of the moderating effect of Informal social support on the relationship between HIV Status Stress and Sexual Risk. To carry out this analysis, the Informal support scale was dichotomized by a median split.

Examination of the point-biserial correlation coefficients showed that Informal social support buffered the effect of HIV Status Stress on Sexual Risk. The relationship was positive and statistically significant when Informal support was below the median ( $r=.28$ ,  $p=.004$ ), but not significant when Informal support was above the median ( $r=.04$ ,  $p=.652$ ). When Informal support was low, greater stress was associated with higher levels of Sexual Risk, but when Informal support was high, stress was not related to Sexual Risk.

Figure 5 illustrates the interaction of HIV Status Stress and Informal Social Support. It is interesting to note that at lower levels of stress, high informal support appears to exacerbate sexual risk behaviors. However, as stress increases, Informal support acts to buffer the impact of stress and reduces sexual risk behaviors.



**Figure 5 The buffering effect of Informal Social Support on the relationship between HIV Status Stress and Sexual Risk.**

## **6. CHAPTER SIX: DISCUSSION**

The main purpose of this study was to investigate the influence of HIV status stress on adherence to HIV/AIDS treatment and prevention. It also examined the mediating role of rejection of chance health locus of control as well as the moderating role of social support (informal and formal). The research was conducted on a sample of 212 people living with HIV/AIDS (PLHAs) in Dar-es-Salaam, Tanzania.

This chapter begins with a discussion on the study results, and locates those findings in the context of the literature. This is followed by a discussion of the study's limitations. The chapter concludes with an assessment of the implications of the study's findings for public health and social work.

### **6.1. Study Findings**

**6.1.1. Sample characteristics.** Less than a quarter of the 212 respondents were men. Although the AIDS epidemic in Africa has impacted men and women in relatively equal proportions (Achieng, 1999), African women are the primary caregivers in their families (Ankrah, Schwartz, & Miller, 1996) and tend to seek help both for themselves and for their whole family. Consistent with their role as caregivers, African women living with HIV/AIDS may be more likely than men to get involved in AIDS Service Organizations (ASOs).

Women also tend to seek ASO support on behalf of their children (Donahue, 1998; Hunter, & Williamson, 2000; Lay, 2001). It is not surprising, therefore, that 189 out of the 212 participants were parents, the majority of whom were women. Also in this sample, 29% of the men and 63% of the women reported being widowed. Widows with children may have an additional motivation for involvement in ASOs. According to Meursing and Sibindi (2000),

supportive counseling establishes supportive interactions. ASO caregivers may facilitate a two-way interaction by which single parent PLHAs can feel supported in their parenting roles.

Although the mean age was nearly the same for men (38.9) as for women (38.20), the youngest female participant was 19 years old while the youngest male was 22 years old. As repeatedly noted in Africa, women tend to be infected at a younger age in comparison with men (Gibbs, 2002; UNAIDS, 2002; UNAIDS/WHO, 2003).

The sample of PLHAs living in Dar-es-Salaam was diverse in terms of region of origin and ethnic representation as well as religion. All regions of Tanzania and most religions were represented in the study's sample. Nearly all participants characterized religion as being very important to them. Interestingly, comparison of birth and current religion suggests a trend towards conversion to non-traditional religions, mainly Pentecostal churches.

The results of this study are consistent with the low level education attainment in Tanzania observed by Galabawa, Kilindo, Sichona, Mwaimu, Kivanda, and Mugussi (2001). Only 36% of the women and 25% of the men had higher than primary level of education. Most of the women, and 60% of the men, could be characterized as what Illife (1987) called the African poor. The majority of respondents were unemployed (90%). However, 50% of the men in the sample reported a monthly income higher than USD 55.00, compared to only 15% of the women.

In terms of general health status, nearly all of the participants (96%) reported having had some of the symptoms of opportunistic infections. However, 51% of the respondents rated their general health status as satisfactory, 28% characterized it as good/very good, and only 21% rated it as poor or very poor.

In terms of life satisfaction, 39% rated their life satisfaction as being very poor or poor, whereas 36% rated it as being satisfactory. Thus, even the PLHAs who perceived their health as being relatively alright are not all satisfied with their general well being. As O'Connell, Skevington, and Saxena (2003) suggest, there is more to life satisfaction than simply the absence of AIDS symptoms.

**6.1.2. Study variables.** As pointed out in prior studies on HIV-related stress, stress impedes prevention (Blaney et al., 2003; Ironson et al., 1994). This study's results shed light on the negative impact of stress on the lives of people living with HIV in Tanzania.

Generally, the study variables were correlated with few of the demographic characteristics. The HIV Status Stress Scale was not associated with any of the demographic indicators. The Formal Social Support Scale, the Rejection of Chance Health Locus of Control measure, and the Adhere Scale were all positively correlated with monthly income. Hence, the study results support the argument that access to financial resources (among other things) contributes to feelings of mastery and control (Syme, 1994).

The inverse correlation between being separated/divorced and informal social support was significant. The negative relationship observed may reflect the loss of support from a spouse and the spouse's immediate and extended family members. On the other hand, the participants' perceptions of low levels of informal support could be a reflection of their withdrawal from support networks when the loss of spouse is combined with being diagnosed with HIV.

Gender was correlated with rejection of chance health locus of control. Women were more likely than men to attribute their ability to adhere to HIV/AIDS treatment and prevention to chance. Age was negatively correlated with Sexual Risk, and this result supports the observed

higher rates of HIV infection among the younger adults, especially females, compared with older adults (NACP, 2001, 2003).

Being married was positively correlated with Sexual Risk. This may be reflective of the observed complacency among married couples regarding practicing safer sex. Married individuals may erroneously assume that those in marriage are at lower risk for HIV infection than adults who are not married. Thus, married couples may be unlikely to use condoms regularly.

The HIV Status Stress Scale was negatively correlated with the Adhere Scale and positively correlated with the sexual risk indicator. Whereas the ability to adhere to HIV/AIDS treatment and prevention declines as HIV status stress increases, the indicator for sexual risk increases as stress rises. Moreover, the Adhere and Sexual Risk measures were negatively correlated with each other. Thus, the participants scoring higher on ability to adhere scored lower on sexual risk and vice versa.

**6.1.3. Hypothesis testing.** As predicted in hypothesis 1a, the HIV Status Stress Scale negatively predicted the Adhere scale and positively predicted the Sexual Risk measure. Not only did high stress significantly predict the PLHAs' diminished ability to adhere to HIV/AIDS prevention, it also predicted their inability to resist sexually risky practices. The stress measure used in this study was not a diagnostic measure of the types of stress the participants had. Hence, the measures that led to these study findings may not be exactly comparable to the measures that led to the findings cited by Erbeling (2001), which have shown a high correlation between unprotected sexual practices by PLHAs and depressed mood. However, a study by Wyatt (1997) has shown that HIV-related stress can cause hopelessness, which may be compared with depressed mood (Erbeling, 2001), and distressed mood (Burkhalter, 1997).

The study results suggest that effective strategies for HIV/AIDS prevention should include stress reduction as a way of reducing sexual risk behaviors. Prior studies (Donnelly, 2003; Erbelding, 2001) have illustrated the complexities of studying sexual behavior in Africa. The complexities range from past socio-political history to present day poverty and gender inequity (Erbelding, 2001). Hence, application of the results of this study to the African experience will be neither straightforward nor easy.

Rejection of chance health locus of control did not significantly correlate with either the HIV Status Stress Scale or the Adhere and Sexual Risk measures, nor did it mediate the relationship between either the HIV Status Stress Scale and these measures or social support. Since neither Hypotheses 1c nor 2c was supported, these findings could be interpreted as lack of support for the original hypotheses regarding the mediating role of internal health locus of control. However, it is important to bear in mind that rejecting chance is not synonymous with internal locus of control. It is possible that respondents could both reject chance and not have internal locus of control. According to Wallston (1993), people can be both "internal" and "external" at the same time. The concept of multidimensional health locus of control involves acknowledging that internality and externality are not necessarily mutually exclusive (Wallston, 1993).

What is clear from the study results, however, is that gender and income significantly influence rejection of chance in health locus of control. The poorer the PLHAs are, especially women PLHAs, the more likely they are to attribute their health behaviors to external forces, i.e. chance locus of control, rather than to their own internal locus of control. In this study, women tended to report less rejection of chance than men.



When the moderating effects of informal and formal social support on the relationship between HIV Status Stress and Adhere and Sexual Risk were tested, the moderating role of informal support was supported in relation to Sexual Risk only. Therefore, Hypothesis 3 was only partially supported.

The interaction between informal social support and HIV Status Stress had a significant effect on Sexual Risk. In situations of high HIV Status Stress, the presence of high informal social support buffered the effect of high HIV Status Stress on Sexual Risk such that risk was lower even when stress was high. These findings support the argument advanced by Paton (2000) that where higher support was associated with higher levels of symptomatology, it was assumed that support was mobilized after stress, or strain, had occurred. Thus, unlike in situations where existing social support responds to stress by buffering its effect on the individual, in this situation, it was the stressful events that created the need to mobilize support. In this study, the informal social support was from networks of family, friends, and peers experiencing the same HIV/AIDS-related stress. A support system that shares the same type of stress, therefore, may tend to cope with that stress in similar ways, thus reinforcing the same type of risk behaviors.

As for the participants' formal social support, moderation was not supported. The interaction between formal social support and HIV Status Stress had no significant effect on either the Adhere or Sexual Risk measures. Thus, formal systems are not benefiting from informal networks at desired levels that promote high adherence to HIV/AIDS treatment and prevention. However, given that only one of the four hypothesized moderation models was significant, the results can only be generalized with caution.

The significance of the interaction effect of informal social support in the relationship between HIV Status Stress and Sexual Risk, however, suggests the importance of embracing the African network of support systems, including both the immediate and extended family, in all strategies for HIV/AIDS prevention. The formal system cannot succeed in bringing about change by itself, and may benefit from the effects of the informal system to bring about change in sexually risky behaviors. Thus, ASOs and health service professionals should recognize that their efforts to curb the spread of HIV/AIDS in Tanzania, specifically, and in Africa, generally, may well depend on how effectively they work with the PLHAs' informal system of social support.

## **6.2. Limitations**

By targeting the individuals living with HIV/AIDS in Dar-es-Salaam, this study addressed what had not been previously investigated among Africans living with HIV/AIDS: the stress associated with their HIV status. There are some limitations in conducting such a study.

One is that being a cross sectional survey it captures data at one point in time. The study could not observe change over time, nor could actual behavior be observed. Moreover, one cannot empirically establish the temporal ordering of events; thus, as in this case, temporal sequencing is derived from theory. Finally, a cross-sectional survey design may not fully control for threats to internal validity.

In addition, the study relied on self-reported information. Self-report studies tend to be prone to social desirability bias (Crowne, & Marlowe, 1964) and, at times, participants may report what they think the researcher wants to hear. This study cannot claim to be entirely free of social desirability. Given that participants were recruited from established ASOs, they may have

under-reported their sexual risk behaviors and over-reported their adherence behaviors to make themselves and their service providers “look good.”

There are other limitations relating to the extent to which the study results can be generalized. Respondents were drawn from among those using the services of two ASOs in Dar-es-Salaam. Thus the findings may reflect the experience and perceptions of the PLHAs who are involved with those agencies and may not be representative of Tanzanians PLHAs generally.

A final limitation is the use of two new instruments (i.e., the HIV Status Stress Scale and the Adherence [Adhere and Sexual Risk] Scale), and one instrument (i.e., Multidimensional Health Locus of Control Scale) that has not been previously applied to studies of African populations. Further works needs to be done to establish the meaning of the concepts entailed in the instruments to an African population. Consequently, determining the reliability and validity of these instruments, merit further investigation.

### **6.3. Social Work and Public Health Implications**

Although the limitations that have been discussed make it hard to generalize the results of this study to the entire population of Tanzanian PLHAs, in particular, and African PLHAs in general, these findings are nevertheless very important. They suggest important directions for future social work and public health research and practice. In pointing to the fact that existing HIV/AIDS prevention related activities by ASOs have yet to achieve the intended objective of reducing sexual risk behaviors, these findings guide the future of social work and public health research and practice in Tanzania.

#### **6.3.1. Future Research**

In terms of both social work and public health research, this study points to new avenues for further research. For example, HIV infection rates in Africa suggest a relative equality

between men and women in terms of their exposure to the disease (Baden, & Wach, 1998). Yet, the results of this study found a significantly lower proportion of men, compared to women, in terms of ASO participation. Future investigations should assess why men use or do not use ASO services. Strategies to recruit males should be tested and evaluated.

Equally important for future research is investigating the reasons why those in this study who were married displayed riskier sexual behaviors than non-married respondents. These results show that there is need to investigate how earlier emphasis on what came to be known as “risk groups” may have created complacency in married couples who may have been made to believe that, by implication, they were “a safe group”. This may have delayed addressing the specific needs of married couples, especially married women, in the strategies for HIV/AIDS prevention (Fiala, 2000), the consequences of which are reflected in the results of this study.

As for the moderating role of informal social support, there is existing literature to show how African informal networks have influenced health seeking behavior and medical decisions in the past. Feierman and Janzen (1992), in a description of a Christian village in the Masasi district of pre-independent southern Tanganyika, reported that an individual “might decide to become a Christian; but when that individual fell seriously ill it was his kinfolk, his *jamaa*, who determined how he should be treated” (p. 270). Future research needs to establish how much power family and kinship networks still have and whether these informal social support sources are still available to influence individuals’ adherence to HIV/AIDS treatment and prevention.

### **6.3.2. Future Social Work and Public Health Practice**

This study’s results will allow Tanzania social work practitioners to learn about the impact of stress on their PLHA clients. Given that HIV Status Stress has shown to negatively impact adherence to HIV/AIDS treatment and prevention, practitioners should introduce

programs that aim at the alleviation of such stress. Evidence-based practices could help to curb the spread of HIV/AIDS in Africa, while building the credibility of social work and public health approaches to working with PLHAs and their family members..

Social work professionals can try building stronger networks of formal support to compliment their client's networks of informal support in order to limit HIV transmission. As pointed out by Perlmutter, Clark, Mangione, Ayotte, and Kessler (2001), health care and social service providers may have to integrate social networks of PLHAs and their families into short-and long-term counseling programs. Given that informal support networks were shown to interact with HIV-related stress to impact sexual risk, identifying and working with clients' informal networks may be the only way to reduce primary and secondary HIV transmission in Africa. Public health practitioners, too, could make effective use of community networks of informal support as conduits for distributing information on HIV/AIDS prevention to community members.

There are several ways to do this without compromising confidentiality. First, clients could be allowed to bring their loved ones into individual counseling sessions. Second, in group work and community interventions, clients could be asked to suggest different approaches to collective bargaining whereby group and community members would design models to enhance compliance with HIV/AIDS treatment and prevention regimes.

Future HIV policies and practices have to be informed by research as well as by the grassroots experience of the AIDS Service Organizations. Hence, social work and public health researchers and practitioners must have a system that encourages dialogue among the infected and affected groups, government policy makers, professional practitioners, and academic researchers. This way, all of the actors in the processes that impact the lives of the Tanzanian PLHAs and their families can develop and implement a shared commitment to reduce HIV

infection and to promote healthful living with HIV/AIDS. The future well being of Tanzanian PLHAs and their families, no less all of the country's citizens, demands no less than this.

## APPENDIX A

### University of Pittsburgh IRB Approval (USA)

**From:** "Nixon, Shannon" <NixonSL@upmc.edu> **Date:** 7/21/2003 9:50:52 AM  
**To:** "'tkaijage@udsm.ac.tz'" <tkaijage@udsm.ac.tz>  
**CC:** "'tjk4@pitt.edu'" <tjk4@pitt.edu>; "'swssw@pitt.edu'" <swssw@pitt.edu>  
**Subject:** RE: IRB #0306105 - Factors Affecting Adherence to ...

Dear Theresa,

I am glad that you have seen the message. I have printed your email and included it with your file. I will pass this on for an approval letter now. You should receive the approval letter by email before the end of the day.

Please note that the Cover Sheet you sent is incorrect--your study is Exempt, and the Exempt Cover Sheet is part of the Exempt application. The Cover Sheet that was sent is for Full Board or Expedited studies. However, your email will suffice since you have explained the financial support. There is no need to send anything else.

Bets of luck!

Thank you,  
Shannon

-----Original Message-----

From: Theresa J. Kaijage & Frederick J. Kaijage  
[mailto:tkaijage@udsm.ac.tz]  
Sent: Saturday, July 19, 2003 5:41 AM  
To: Nixon, Shannon  
Cc: 'tjk4@pitt.edu'; 'tkaijage@udsm.ac.tz'; 'swssw@pitt.edu'  
Subject: Re: IRB #0306105 - Factors Affecting Adherence to ...

- > Dear Theresa and Dr. Wexler,
- >
- > Regarding your IRB submission named above, there is only one comment that
- > needs to be addressed:
- >
- > IRB Cover Sheet:
- > Page 1, Source of Financial Support, please clarify who will

> pay for the costs of this study. Participants are being offered \$10.00 to  
> cover costs of arranging the interview regardless of whether they complete  
> the interview. Two hundred participants are anticipated.  
>  
> Could you please revise the first page of the form as noted and just send  
> it  
> back to me as an attachment in an email? It is fine that the form will  
> not  
> be signed again. If you have any questions, please email me.  
>  
> Thanks,  
> Shannon  
>

Dear Shannon,

I am sorry that I did not see this message till today. I have had problems accessing my messages but finally I am able to do so from home. I am sending you the attachment you have requested immediately and I have indicated that the funding is from family income, which is the case so far.

Theresa

> Shannon Nixon  
> Research Review Coordinator  
> University of Pittsburgh Institutional Review Board  
> 3500 Fifth Avenue, Suite 105  
> Pittsburgh, PA 15213  
> Phone: 412-578-8568  
> Fax: 412-578-8566



## **APPENDIX B**

### **NIMRI (National Institute for Medical Research) IRB Approval (Tanzania)**

# NATIONAL INSTITUTE FOR MEDICAL RESEARCH

Telephone 255 22 2130770/2131864  
Telex 41919 NIMR TZ  
Telegrams MEDSEARCH  
Telefax 255 022 2130660/2131864  
E-mail: [headquarter@nimr.or.tz](mailto:headquarter@nimr.or.tz)



Road Ocean  
P.O. Box 9653  
Dar es Salaam  
Tanzania

Our Ref: NIMR/HQ/Vol.IX/R.8a/282  
Your Ref:

July 29, 2003

Ms Theresa J Kaijage  
P.O. Box 35133,  
Dar es Salaam.

Dear Kaijage,

**RE: Clearance for the study entitled "Factors affecting adherence to HIV/AIDS treatment and prevention in Tanzanians living with HIV/AIDS in Dar es Salaam" (Kaijage J K)**

The heading above refers.

With this letter, clearance is hereby granted to the above study to be conducted in Tanzania.

The Principal Investigator will have to ensure that the following are fulfilled:

1. Progress report is made available to MoH and NIMR every six months.
2. Permission to publish the results is obtained from NIMR and manuscript being attached before any publication is made.
3. Copies of final publications are made available to MoH and NIMR for action and record

Sincerely yours

Secretariat  
Health Research Ethics Review Sub-Committee

## **APPENDIX C**

### **SHDEPHA (English)**

SERVICE HEALTH AND DEVELOPMENT FOR PEOPLE LIVING POSITIVELY WITH  
HIV/AIDS  
(SHDEPHA+NATIONAL ASSOCIATION NETWORK)

MUHEZA ST. NO. 3,  
P.O BOX 13713,  
DAR ES SALAAM,  
TANZANIA.  
Tel: 255-022-2181849/50  
Fax: 255- 022-2181849  
Email: shdepha3@yahoo.com

Our Ref: SHF/05/1124

Date: 11<sup>th</sup> June, 2003

THERESA J.KAIJAGE,  
3245 KENNETT SQUARE,  
PITTSBURG, PA 15213.  
U.S.A.

Dear Maddam,

RE: RESEARCH PERMISSION.

Refer to the heading above.

The Service Health and Development for People Living Positively with HIV/AIDS (SHDEPHA+) a National Association Network of PLHAs is congratulates you and wishes you well in all your endeavours, and express willingly to collaborate with you in area of HIV-related programmes. Hence permission is granted for your Research with SHDEPHA+ National Association Network members, staffs and clients.

With Best Wished from us all.

Yours Sincerely.



Joseph B.Katto  
NATIONAL CHAIRPERSON  
SHDEPHA+ NETWORK.



## **APPENDIX D**

### **WAMATA Letter (English)**



## WAMATA Dar Branch

WALIO KATIKA MAPAMBANO NA AIDS TANZANIA

P.O. Box 32960

Dar es Salaam

Tel: (022)-2700282

Mobile: 0744 268990

E-mail: wamata@africaonline.co.tz

WMT/DARB/GEN/9/VOL.3/19

30 May 2003

Theresa J. Kaijage  
3245 Kennett Square  
Pittsburg, PA 15213  
United States of America.

Dear Kaijage,

**REF: PERMISSION TO CONDUCT RESEACH**

Reference is made to your request letter in which you indicated intention to conduct the research at SHDEPHA+ and WAMATA.

I am pleased to inform you that permission has been granted and we are eager to receive you and provide all necessary support to make the study a success. The 200 interviewees are easy to get from our clientele group of over 4000 PLHAs

The two organizations are willing to collaborate and work on logistics that will facilitate easy access to respondents and avoid duplication of names. Upon your arrival you may also get access to other organizations with similar activities and draw more interviewees.

**WAMATA** management and leadership welcome you for the research in which we believe the findings could be used to develop better HIV/AIDS program and enrich available service delivery systems.

Thank you.

Yours,

**B.T. Mubondo  
EXECUTIVE OFFICER**

## **APPENDIX E**

### **Mr. Mubondo Letter (English)**



5<sup>th</sup> July 2003

Dear .....

### **Participation in Research**

WAMATA being an AIDS Service Organization (ASO) that serves people living with HIV/AIDS, widows, and orphans, has been collaborating with other organizations in different activities since 1989. In collaboration with SHDEPHA+, WAMATA has agreed to host the research conducted by Mrs Theresa J. Kaijage who is doctoral candidate at the University of Pittsburgh. This research will involve a random sample of some participants drawn from our members. We are asking you to feel free to participate as volunteers to the study knowing very well that confidentiality will be strictly observed throughout the period of research and afterwards.

If you agree to be a volunteer for the study if your name is selected, please sign below.

Thank you.

Yours,

**B.T. Mubondo**  
**Executive Officer**

**I,..... agree to volunteer for this research if I am selected.**



## **APPENDIX F**

### **Cover Letter (English)**

June, 24, 2003

Dear Research Respondent,

I am a doctoral student in the School of Social Work at the University of Pittsburgh, and I am conducting research on “Factors Affecting Adherence to HIV/AIDS Treatment and Prevention in Tanzanias Living with HIV/AIDS in Dar-es-Salaam”.

I want to thank you in advance for taking the time to consider if you could be a volunteer for this research as participant in an interview. I would like to interview you and ask you some questions about your experiences since your HIV diagnosis, and your adherence to HIV/AIDS treatment and prevention.

There will not be any risk or harm to you in answering any of the questions, but some of the questions may involve things you feel are private to you. You do not have to respond to any questions that you do not want to answer. Any information that I learn from this study will be kept confidential. That means that no one will be able to personally identify you since there will be nothing on the questionnaire that will indicate your identity. No one will be identified in any description or publication of this research.

Although there will not be any direct benefit to you from this study, the results of the study will most likely assist in planning of future programs. You will get \$10.00 to cover your cost of arranging for our meeting to do this interview whether you do, or do not, complete the interview.

If you have any questions about this research, please contact me at 270-0094 in Dar-es-Salaam, or by e-mail at [tjk4@pitt.edu](mailto:tjk4@pitt.edu), and [tkaijage@udsm.ac.tz](mailto:tkaijage@udsm.ac.tz). If there are any questions relating to your rights as a participant in this study, you can call the Human Subject Protection Advocate at the University of Pittsburgh IRB Office (412-578-8570), or contact the National Institute for Medical Research (NIMRI) in Dar-es-Salaam at [headquarters@nimri.or.tz](mailto:headquarters@nimri.or.tz).

Sincerely,

Theresa J. Kaijage  
School of Social Work  
University of Pittsburgh

## APPENDIX G

### Consent Form (English)

#### Informed Consent

This study is being conducted to explore and explain the on “Factors Affecting Adherence to HIV/AIDS Treatment and Prevention in Tanzanias Living with HIV/AIDS in Dar-es-Salaam”.

If you agree to participate you will be asked to be interviewed by me or my research assistant for up to one hour during the period between August and October, 2003.

The foreseeable risks or discomforts include being questioned on some risk behaviors that could hinder adherence to HIV/AIDS treatment and prevention. Therefore, some of the questions may involve things you feel are private to you.

Your participation is voluntary, and you may withdraw from the study at any time and for any reason. There is no penalty for not participating or withdrawing. The personal benefits for participation include: the results of the study will most likely assist in the designing of future programs, which could benefit many people; you will get \$2.00 to cover your cost of arranging for our meeting to do this interview whether you do, or do not, complete the interview.

There are no costs to you or any other party.

All data collected in this study will be confidential; all person-identifiable data will be coded so that you cannot be identified.

This study is being conducted by Theresa J. Kaijage at the University of Pittsburgh in collaboration with SHDEPHA+ and WAMATA. She may be reached by phone at her home: 270-0094, or by e-mail at [tjk4@pitt.edu](mailto:tjk4@pitt.edu), and [tkaijage@udsm.ac.tz](mailto:tkaijage@udsm.ac.tz) for questions or complaints. Also her advisor can be reached by e-mail at Sandy Wexler <[swssw+@pitt.edu](mailto:swssw+@pitt.edu)>.

You may also contact the Human Subject Protection Advocate at the University of Pittsburgh IRB Office (412-578-8570), or the National Institute for Medical Research (NIMRI) in Dar-es-Salaam at [headquarters@nimri.or.tz](mailto:headquarters@nimri.or.tz) if you have any questions or comments regarding your rights as a participant in this research.

This project has been reviewed according to the University of Pittsburgh Institutional Review Board procedures governing your participation in this research.

I have read this form and agree to participate in the study.

Signature	Date:
Witness Signature	Date:

## APPENDIX H

**Kiswahili translation: Consent Form, Cover letter, Mr. Mubondo letter, etc.**

### CHUO KIKUU CHA PITTSBURGH

Shule ya Ustawi wa Jamii

26 Juni 2003

Ndugu,

Mimi ni mwanachuo wa uzamivu katika Idara ya Ustawi wa Jamii, Chuo Kikuu cha Pittsburgh na ninafanya utafiti kuhusu “Mambo Yanayoathiri Uzingatiaji wa Tiba na Kinga kwa Watanzania waishio na Virusi vya Ukimwi, Dar es Salaam”.

Ninapenda kukushukuru kwa kutumia muda wako ili kuona kama unaweza kuwa mshiriki wa kujitolea katika mahojiano katika utafiti huu. Nitakuuliza maswali kuhusu uzoovu wako tangu ulipogundua kuwa una virusi vya ukimwi na uzingativu wako katika tiba na kinga.

Hakutakuwa na matatizo au madhara yoyote katika kujibu swali lolote, ingawa baadhi ya maswali yanaweza kuhusu mambo ambayo unaona ni siri kwako. Endapo unaona swali ni la siri na hutaki kulijibu, basi usilijibu. Habari yoyote itakayopatikana kutokana na utafiti huu itakuwa ni siri. Aidha, hakuna mtu atakayejua umetoa taarifa kwa sababu hakuna maelezo yoyote kwenye dodoso zinazokutambulisha. Isitoshe, hakuna mtu yeyote aliyehusishwa katika utafiti huu ambaye atatambulishwa kwa njia yoyote ile; iwe kwa maelezo au machapisho ya baadaye.

Ingawa hutapata faida ya moja kwa moja kutokana na utafiti huu, matokeo ya utafiti huu yatasaidia katika kupanga mipango ya baadaye. Pia, utapata shilingi elfu mbili kwa ajili ya gharama za kukutana kwa usaili hata kama hutakamilisha usaili.

Endapo una maswali yoyote kuhusu utafiti huu, tafadhali wasiliana nami kwa simu namba 270-0094 ya hapa Dar es Salaam, au kwa barua pepe [tjk4@pitt.edu](mailto:tjk4@pitt.edu), na [tkaijage@udsm.ac.tz](mailto:tkaijage@udsm.ac.tz). Endapo kuna ukiukaji wa haki zinazokuhusu wewe kama mshiriki katika utafiti huu, unaweza kuwasiliana na Wakili wa Haki za Binadamu za Wahojiwa, Chuo Kikuu cha Pittsburgh ofisi ya IRB (412-578-8570), au wasiliana na Taasisi ya Taifa ya Utafiti wa Tiba (TTUT) Dar es Salaam [headquarters@nimiri.or.tz](mailto:headquarters@nimiri.or.tz).

Wako Mwaminifu,

Theresa J. Kaijage  
Shule ya Ustawi wa Jamii  
Chuo Kikuu cha Pittsburgh

## UTARATIBU WA MAKUBALIANO YA USHIRIKI

Utafiti huu umelenga kuchunguza “Mambo Yanayoathiri Uzingatiaji wa Tiba na Kinga kwa Watanzania waishio na Virusi vya Ukimwi, Dar es Salaam”.

Endapo utakubali kushiki katika utafiti huu, mimi nitakuuliza maswali au mtafiti msaidizi. Usaili utakuwa ni saa moja. Usaili unaweza kufanyika nyumbani au sehemu nyingine unayoona kuwa inafaa. Kwa utafiti huu, usaili utafanyika miezi ya Augusti, Septemba na Oktoba 2003.

Katika utafiti huu, tatizo linalojitokeza ni kuhusu kuwauliza mambo ambayo mnaona kuwa ni siri. Baadhi ya maswali yanaweza kukutaka ufikiri kuhusu siku zilizopita au zijazo, jambo hili kwa kiasi fulani linaweza lisikufurahishe.

Ushiriki wako ni wa hiari, kwa hiyo, unaweza kukataa kujibu swali lolote au kujitoa kabisa katika utafiti huu wakati wowote na kwa sababu yoyote. Hakuna adhabu kwa kutoshiriki au kujitoa katika utafiti.

Faida binafsi unazoweza kupata kwa kushiriki katika utafiti huu ni pamoja na: (1) matokeo ya utafiti huu kusaidia katika mipango ya baadaye ambayo inaweza kuwasaidia watu wengi (2) utapata shilingi elfu mbili (\$2) kwa ajili ya gharama za kukutana kwa usaili. Fedha hizi utapewa hata kama hutamaliza usaili.

Hakuna malipo yoyote utakayotakiwa kutoa.

Data zitakazopatikana katika utafiti huu zitakuwa ni siri, zile zinazoweza kumtambulisha mhusika zitatumia vifupisho au ishara ili mhusika asiweze kufahamika.

Utafiti huu unafanywa na Theresia J. Kaijage katika Chuo Kikuu cha Pittsburgh kwa kushirikiana na SHDEPHA+ na WAMATA. Unaweza kuwasiliana nae kwa simu ya nyumbani kwake, Dar es Salaam namba 270-0094, au barua pepe : [tkj4@pitt.edu](mailto:tkj4@pitt.edu), au [tkaijage@udsm.ac.tz](mailto:tkaijage@udsm.ac.tz) kwa maswali au malalamiko. Pia, unaweza kuwasiliana na mshauri wake kwa kuitumia barua pepe ifuatayo: Sandy Wexler [swssw+@pitt.edu](mailto:swssw+@pitt.edu).

Vilevile unaweza kuwasiliana na Wakili wa Haki za Binadamu za Wahojiwa, Chuo Kikuu cha Pittsburgh ofisi ya IRB (412-578-8570), au Taasisi ya Taifa ya Utafiti wa Tiba (TTUT) Dar es Salaam, [headquarters@nimri.or.tz](mailto:headquarters@nimri.or.tz) endapo una maswali au maoni kuhusu haki zako kama mshiriki katika utafiti huu.

Nimesoma fomu hii na nimekubali kushiriki katika utafiti huu.

Sahihi	Tarehe
Sahihi ya Shahidi	Tarehe

5<sup>th</sup> Julai 2003

Mpendwa

**YAH: KUSHIRIKI KATIKA UTAFITI**

WAMATA likiwa ni shirika linalotoa huduma kwa watu wanoishi na virusi vya UKIMWI, watoto yatima na wajane tumekuwa tukishirikiana na watu wengine na mashirika mbalimbali. Huduma zetu ni za muda mrefu tangu mwaka 1989 nasi kama WAMATA na wenzetu wa SHDEPHA+ tumekubali kushiriki katika utafiti unaoongozwa na Mama Theresa Kaijage ambaye anasoma Chuo Kikuu cha Pittsburg. Katika utafiti huu watachaguliwa watu watakaohojiwa na endapo utachaguiwa tunakuomba ushiriki wako wa dhati. Ushiriki ni wa hiari na taarifa utakazotoa ni za siri na zitaendelea kuwa siri hata baada ya utafiti.

Endapo unakubali kushiriki kwa hiari unaombwa kuweka sahihi yako katika nafasi iliyoachwa hapo chini.

Ahsante sana.

Wako,

**B.T. Mubondo**

**AFISA MTENDAJI**

**Mimi ..... nakubali kushiriki katika utafiti kwa hiari yangu.**

Mpendwa Mama Kaijage,

Salaam,

Nashukuru sana kwa kuchagua utafiti wako uhusishe WAMATA. Napenda kukuhakikishia kuwa idadi ya washiriki unayotaka utaipata bila shaka. Lakini kama unavyofahamu wengi wa wanachama wetu/walengwa ndio hao hao wanaozunguka PASADA na SHIDEPHA+, hivyo pengine itabidi dodoso (questionarie) lako litenganishe hilo. Njia rahisi itakuwa kutayarisha majina ya WASHIRIKI kutoka kila shirika ili yachambuliwe yale yatakayoonekana kujitokeza zaidi ya mara moja.

Suala la kutotumia wafanyakazi wa WAMATA ni zuri, kwa sababu uliyotoa, lakini ni vigumu kuwaweka nje kabisa maana ndio wanaofahamu hao walengwa wanakoishi na majina yao.

Anuani ya SHIDEPHA+ ni: Mkurugenzi  
SHIDEPHA+  
S.L.P. 13713  
DAR ES SALAAM  
TEL/FAX:255-22- 2181849  
[e-mail:shdepha3@yahoo.com](mailto:shdepha3@yahoo.com)

Anuani ya PASADA ni: Director  
PASADA  
P.O. Box 70225  
DAR ES SALAAM  
Tel:2865451  
[e-mail:pasada@intafrica.com](mailto:pasada@intafrica.com)

## **APPENDIX I**

### **Questionnaire (English)**



## DEMOGRAPHIC CHARACTERISTICS AND BACKGROUND

1. Sex: \_\_\_\_\_ 1 Female \_\_\_\_\_ 2 Male

2. What is your age as of your last birthday? \_\_\_\_\_ (years)

3. What is the district/region of your Birth?

- \_\_\_\_\_ 1 Arusha
- \_\_\_\_\_ 2 Coastal
- \_\_\_\_\_ 3 Dar-es-Salaam
- \_\_\_\_\_ 4 Dodoma
- \_\_\_\_\_ 5 Iringa
- \_\_\_\_\_ 6 Kagera
- \_\_\_\_\_ 7 Kigoma
- \_\_\_\_\_ 8 Kilimanjaro
- \_\_\_\_\_ 9 Lindi
- \_\_\_\_\_ 10 Manyara
- \_\_\_\_\_ 11 Mara,
- \_\_\_\_\_ 12 Mbeya
- \_\_\_\_\_ 13 Morogoro
- \_\_\_\_\_ 14 Mtwara
- \_\_\_\_\_ 15 Mwanza
- \_\_\_\_\_ 16 Rukwa
- \_\_\_\_\_ 17 Ruvuma
- \_\_\_\_\_ 18 Singida
- \_\_\_\_\_ 19 Sinyanga
- \_\_\_\_\_ 20 Tabora
- \_\_\_\_\_ 21 Tanga
- \_\_\_\_\_ 22 Zanzibar and Pemba Isles
- \_\_\_\_\_ 23 Outside Tanzania (Where?) \_\_\_\_\_

4. What religion were you raised in?

- \_\_\_\_\_ 1 Islam
- \_\_\_\_\_ 2 Catholic
- \_\_\_\_\_ 3 Lutheran
- \_\_\_\_\_ 4 Pentecostal Churches
- \_\_\_\_\_ 5 Other \_\_\_\_\_

5. What religion are you practicing now?

- \_\_\_\_\_ 1 Islam
- \_\_\_\_\_ 2 Catholic
- \_\_\_\_\_ 3 Lutheran
- \_\_\_\_\_ 4 Pentecostal Churches
- \_\_\_\_\_ 5 Other \_\_\_\_\_

6. How important is your religion to you now?  
\_\_\_1 Not important \_\_\_2 Important \_\_\_3 Very Important

7. What level of education did you complete?

- \_\_\_1 None at all
- \_\_\_1 Primary School (and under)
- \_\_\_2 Secondary School
- \_\_\_3 Vocational Training
- \_\_\_4 High School
- \_\_\_5 Diploma
- \_\_\_6 Advanced Diploma
- \_\_\_7 Postgraduate Diploma
- \_\_\_8 Bachelor's
- \_\_\_9 Master's
- \_\_\_10 Ph.D.

8. Are you currently:

- \_\_\_1 Employed?
- \_\_\_2 Retired? or
- \_\_\_3 Unemployed?

8a. If employed:

How many hours per week do you work? \_\_\_\_\_ (hours).

9. Are you involved in Informal Sector Employment?

- \_\_\_1 Yes. \_\_\_0 No.

10. What is your income:

\_\_\_\_\_.\_\_ Per Month?

11. Are you currently:

- \_\_\_1 Married?
- \_\_\_2 Single?
- \_\_\_3 Separated?
- \_\_\_4 Divorced?
- \_\_\_5 Widowed?

11a. If Married:

Are you in a polygamous marriage?

- \_\_\_1 Yes. \_\_\_0 No.

11b. If you were married in the past:

Were you in a polygamous marriage? \_\_\_1 Yes \_\_\_0 No.

11c. If Single, Separated, Divorced, or Widowed:

Do you currently have a steady partner? \_\_\_1 Yes. \_\_\_0 No.

12. Do you have another sex partner besides your spouse/steady partner?

\_\_\_ 1 Yes. \_\_\_ 0 No.

13. To your knowledge, is your steady partner/spouse also HIV+?

\_\_\_ 1 Yes. \_\_\_ 0 No. \_\_\_ 2 Don't Know.

14. Do you have children?

\_\_\_ 1 Yes. \_\_\_ 0 No.

14a. If Yes:

How many? \_\_\_\_\_

14b. If Yes:

How many children under age 18 are living with you now? \_\_\_\_\_

15. Do you own the house/flat (apartment) that you are now living in?

\_\_\_ 1 Yes. \_\_\_ 0 No.

15a. If not:

Do you rent the house/room/flat (apartment) that you are now living in?

\_\_\_ 1 Yes. \_\_\_ 0 No.

15b. If you do not pay rent, is the house/room/flat provided by someone you know?

\_\_\_ 1 Yes. \_\_\_ 0 No.

15c. State your relationship to the person providing housing? \_\_\_\_\_.

1.Parent 2.Brother 3.Sister 4.Relative 5.Friend 6.Employer 7. NA.

16. In total how many people live here with you now? \_\_\_\_\_

16a. How many of the people living with you are relatives' children under 18 years of age? \_\_\_\_\_

17. Do you own a house somewhere else? \_\_\_ 1 Yes. \_\_\_ 0 No.

18. When do you think you were infected with HIV? \_\_\_ Month. \_\_\_ Year.

19. When were you diagnosed with HIV? \_\_\_ Month. \_\_\_ Year.

20. Have you developed any AIDS symptoms? \_\_\_ 1 Yes. \_\_\_ 0 No.

20a. If Yes:

When did symptoms first begin to appear? \_\_\_ Month. \_\_\_ Year.

20b. If Yes:

Which of the following symptoms have you had so far?

abdominal pain \_\_\_ 1 Yes \_\_\_ 0 No

any discharge	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
any pain/burning when urinating	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
candidiasis or oral thrush	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
cough	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
cryptococcus/meningitis	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
diarrhea	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
fatigue	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
fever	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
loss of appetite	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
kaposi's sarcoma (KS)	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
malaria	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
night sweats	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
pneumonia	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
skin rash	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
tuberculosis(TB)	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
vomiting	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
weight loss	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No

21. Are you on anti-retroviral (ARV) drugs now? ☐ 1 Yes. ☐ 0 No.

21a. If Yes:

When did you start anti-retroviral treatment?  Year.

21b. If Yes: Do you know the arv combination of drugs? ☐ 1 Yes ☐ 0 No. ☐ N.A.

21c. What of the following combination of ARV drug treatment are you on?

Duovir (Zidovudine (ATZ) 300mg) + Lamivudine 150 mg) + EFAVIR (Efavirenz 200mg)  
= USD 67.00 per month (pm) ☐ 1 Yes. ☐ 0 No.

DUOVIR + VIRAMUNE/NEVUMUNE (Nevirapine 200 mg)

= USD72/42.00 pm ☐ 1 Yes. ☐ 0 No. ☐ N.A.

TRIOMUNE 40mg [Stavudine (d4T) 40 mg + Lamivudine (3TC) 150 mg + Nevirapine 200 mg]

= USD 33.00 ☐ 1 Yes. ☐ 0 No. ☐ N.A.

STAVIR 40mg (Stavudine 150mg) + LAMIVIR 150mg + EFAVIR 200mg

= USD 60.00 pm. ☐ 1 Yes. ☐ 0 No. ☐ N.A.

Stavudine 40/30 + Didanosine 200 mg (ddi) + Efavir/Nevirapine

=USD 33.00 pm. ☐ 1 Yes. ☐ 0 No. ☐ N.A.

Duovir+Indnavir 400mg =USD72.00 pm ☐ 1 Yes ☐ 0 No. ☐ N.A.

Stavir 40mg+Lamivir 150) Indivan pm =USD33 ☐ 1 Yes ☐ 0 No. ☐ N.A.

22. Are you on any other types of treatment? ☐ 1 Yes ☐ 0 No.

22a. If Yes:  
Which are they? \_\_\_\_\_.

22b. If Yes:  
When did you start this treatment? \_\_\_\_\_ Year.

23. Do you use any illicit drugs? \_\_\_\_ 1 Yes. \_\_\_\_ 0 No.

23a. If Yes:  
What are they? \_\_\_\_\_.

23b. If Yes,  
do you use any drug-injecting Needles? \_\_\_\_1 Yes. \_\_\_\_0 No. \_\_\_\_N.A.

23c. If Yes,  
do you share drug-injecting needles with your friends? \_1 Yes \_0 No. \_\_N.A.

24. How many ASOs do you belong to? \_\_\_\_1 Yes. \_\_\_\_0 No.

25. When did you first join an ASO? \_\_\_\_ 1 Yes. \_\_\_\_0 No.

26. In general, would you rate your health as:

- \_\_\_\_ 1 Poor
- \_\_\_\_ 2 Satisfactory
- \_\_\_\_ 3 Good
- \_\_\_\_ 4 Very Good

27. In general, would you rate the quality of your life as:

- \_\_\_\_ 1 Very Poor
- \_\_\_\_ 2 Poor
- \_\_\_\_ 3 Satisfactory
- \_\_\_\_ 4 Good
- \_\_\_\_ 5 Very Good

28. Before we finish, is there anything else you would like to tell me about your experience with adherence to HIV/AIDS treatment and prevention?

I wish to thank you for your participation in this research and for your cooperation in completing this interview.

## MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL (MHLC) SCALES

Each item below is a belief statement about your HIV/AIDS related medical condition. For each item I would like you to tell me if you agree or disagree with that statement. This is a measure of your personal beliefs; obviously there are, no right or wrong, answers. [*Interviewer Instructions: Read the statement to the respondent. First, ask if he or she Agrees or Disagrees. Then, ask “would you say you strongly agree (or disagree), moderately agree (or disagree), or slightly agree (or disagree)?”*]

1=STRONGLY DISAGREE (SD)

2=MODERATELY DISAGREE (MD)

3=SLIGHTLY DISAGREE (D)

4=SLIGHTLY AGREE (A)

5=MODERATELY AGREE (MA)

6=STRONGLY AGREE (SA)

		SD	MD	D	A	MA	SA
1	If my condition worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my condition, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15	If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my condition will get better.	1	2	3	4	5	6
17	If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6

### HIV Status Stress (HSS) Scale

I am going to read you a list of statements about ways you may have felt since receiving your HIV diagnosis. For each statement, please tell me if, since your HIV diagnosis, you have felt that way Never, Rarely, Sometimes, Usually, or Always. If a statement does not apply to you, please let me know: Not Applicable (NA).

	Never 1	Rarely 2	Sometimes 3	Usually 4	Always 5	NA 8
1 Accepting my HIV status has been hard for me.	1	2	3	4	5	8
2 I worry about how to prevent HIV from developing into AIDS.	1	2	3	4	5	8
3 I find living positively with HIV/AIDS difficult to do.	1	2	3	4	5	8
4 I no longer have big plans for my future.	1	2	3	4	5	8
5 Due to my HIV status, it is hard to have intimate relationships.	1	2	3	4	5	8
6 I don't find sex pleasurable any more.	1	2	3	4	5	8
7 My marriage has been in trouble because of my HIV status.	1	2	3	4	5	8
8 I have had problems making my children accept my HIV status.	1	2	3	4	5	8
9 I have had problems making my children accept my HIV status.	1	2	3	4	5	8
10 I worry about not having enough time left before I die.	1	2	3	4	5	8
11 I regret having disclosed my HIV status to my spouse/partner.	1	2	3	4	5	8
12 Due to my HIV status, I have become embarrassed by how I look.	1	2	3	4	5	8
13 I regret that my HIV status is known to my neighbors.	1	2	3	4	5	8
14 I worry about what will happen to my family when I die.	1	2	3	4	5	8
15 I regret that I can no longer contribute much to my/my family's support.	1	2	3	4	5	8
16 I fear that people know my HIV status just by looking at me.	1	2	3	4	5	8
17 I worry about not being able to get the care that I need.	1	2	3	4	5	8
18 I worry about the day when I am not able to care for myself.	1	2	3	4	5	8
19 I feel like giving up on life altogether.	1	2	3	4	5	8
20 I do not think it worthwhile to make plans for the future.	1	2	3	4	5	8
21 I regret that I can no longer do my job well because of my HIV status.	1	2	3	4	5	8
22 I do not have money for all the things that I need to keep healthy.	1	2	3	4	5	8
23 I fear that I will become a burden on my family.	1	2	3	4	5	8
24 I worry about the way AIDS symptoms have changed my looks.	1	2	3	4	5	8
25 I feel ashamed when my neighbors talk about my past.	1	2	3	4	5	8
26 I regret that I can no longer work as much because of my HIV status.	1	2	3	4	5	8
27 I worry that I could have a child who is HIV +.	1	2	3	4	5	8
28 I worry about not being able to attract a partner who is not HIV +.	1	2	3	4	5	8
29 I regret all the things that I have had to give up doing because of HIV.	1	2	3	4	5	8
30 I worry about dying from AIDS.						

**Source of Social Support (SOSS) Scale**  
**A. Emotional Support**

I am going to read you a list of persons. Since your HIV diagnosis, how much Emotional Support is available to you from each of these people. By emotional support, I mean acceptance, advice, freedom to talk openly about your HIV status, ability to confide in, ability to share grief, and the like. Please tell me if the amount of emotional support available to you from each person is: None At All, A Little, A Fair Amount, Quite A Bit, or A Great Deal. Give me the answer that best applies to your situation. If a category of persons does not apply to you, just let me know: Not Applicable (NA).

None at all	A little	A fair amount	Quite a bit	A great deal	NA
1	2	3	4	5	8

**A. Emotional Support**

<b>Person(s)</b>						
Spouse/Partner.....	1	2	3	4	5	8
Children.....	1	2	3	4	5	8
Mother.....	1	2	3	4	5	8
Father.....	1	2	3	4	5	8
Brother(s).....	1	2	3	4	5	8
Sister(s).....	1	2	3	4	5	8
In-laws.....	1	2	3	4	5	8
Paternal Relatives.....	1	2	3	4	5	8
Maternal Relatives.....	1	2	3	4	5	8
Neighborhood/Community	-	-	-	-	-	-
Solidarity Group Member(s)...	1	2	3	4	5	8
Employer.....	1	2	3	4	5	8
Workmates.....	1	2	3	4	5	8
Traditional Healer	1	2	3	4	5	8
Faith Healer	1	2	3	4	5	8
Medical Personnel.....	1	2	3	4	5	8
ASO Clinical Team.....	1	2	3	4	5	8
ASO members.....	1	2	3	4	5	8
Friends.....	1	2	3	4	5	8



**Source of Social Support (SOSS) Scale**  
**B. Practical Support**

Continue thinking about those same persons. Now, I'm interested in finding out how much Practical Support is available to you from each. By practical support, I mean help with finances, transportation, house chores, baby-sitting, housing, clothing, food supplies, medical supplies, or children's education. Since your HIV diagnosis, is the amount of practical support available from each person: None At All, A Little, A Fair Amount, Quite A Bit, or A Great Deal. Give me the answer that best applies to your situation. Again, let me know if a category of persons does not apply to you: Not Applicable (NA).

None at all	A little	A fair amount	Quite a bit	A great deal	NA
1	2	3	4	5	8

**B. Practical Support**

<b>Person(s)</b>						
Spouse/Partner.....	1	2	3	4	5	8
Children.....	1	2	3	4	5	8
Mother.....	1	2	3	4	5	8
Father.....	1	2	3	4	5	8
Brother(s).....	1	2	3	4	5	8
Sister(s).....	1	2	3	4	5	8
In-laws.....	1	2	3	4	5	8
Paternal Relatives.....	1	2	3	4	5	8
Maternal Relatives.....	1	2	3	4	5	8
Neighborhood/Community	-	-	-	-	-	-
Solidarity Group Member(s)...	1	2	3	4	5	8
Employer.....	1	2	3	4	5	8
Workmates.....	1	2	3	4	5	8
Traditional Healer	1	2	3	4	5	8
Faith Healer	1	2	3	4	5	8
Medical Personnel.....	1	2	3	4	5	8
ASO Clinical Team.....	1	2	3	4	5	8
ASO members.....	1	2	3	4	5	8
Friends.....	1	2	3	4	5	8

**Source of Social Support (SOSS) Scale**  
**C. Informational Support**

Finally, I want to ask you about the amount of Informational Support available to you from each of these people. Informational support includes technical information, informational on treatment/prevention, referral to unfamiliar resources/services, and the like. For each person, please tell me if the amount of informational support available to you since your HIV diagnosis is: None At All, A Little, A Fair Amount, Quite A Bit, or A Great Deal. Give me the answer that best applies to your situation. If a category of persons does not apply to you, let me know: Not Applicable (NA).

None at all	A little	A fair amount	Quite a bit	A great deal	NA
1	2	3	4	5	8

**C. Informational Support**

<b>Person(s)</b>						
Spouse/Partner.....	1	2	3	4	5	8
Children.....	1	2	3	4	5	8
Mother.....	1	2	3	4	5	8
Father.....	1	2	3	4	5	8
Brother(s).....	1	2	3	4	5	8
Sister(s).....	1	2	3	4	5	8
In-laws.....	1	2	3	4	5	8
Paternal Relatives.....	1	2	3	4	5	8
Maternal Relatives.....	1	2	3	4	5	8
Neighborhood/Community	-	-	-	-	-	-
Solidarity Group Member(s)...	1	2	3	4	5	8
Employer.....	1	2	3	4	5	8
Workmates.....	1	2	3	4	5	8
Traditional Healer	1	2	3	4	5	8
Faith Healer	1	2	3	4	5	8
Medical Personnel.....	1	2	3	4	5	8
ASO Clinical Team.....	1	2	3	4	5	8
ASO members.....	1	2	3	4	5	8
Friends.....	1	2	3	4	5	8

## Adherence Scale

Now I'm going to read you a list of statements that describe things people may do after they learn they are HIV+. You may have engaged in each of these behaviors. Please tell me if the statement reflects what you do: Never, Rarely, Sometimes, Usually, or Always. If a statement does not apply to you, please tell me: Not Applicable (NA).

	Never 1	Rarely 2	Sometimes 3	Usually 4	Always 5	NA 8	
1							I do not eat a balanced diet.....
2							I do what my faith healer tells me regarding my HIV/AIDS treatment...
3							I reserve time for myself to maintain my health.....
4							I make sure I get the rest I need.....
5							I take all my medication as I am supposed to.....
6							I do not take any food supplements to boost my immunity.....
7							I use a condom whenever having sex .....
8							I do not follow the treatment my traditional healer has given me...
9							I attend the ASO clinic for my HIV/AIDS treatment.....
10							I do not remember taking my medication if someone does not remind me.....
11							I have a planned program for exercise.....
12							I have sex with more than one partner.....
13							I follow the treatment plan my doctor has given me.....
14							I do not seek counseling for my HIV-related problems...
15							I have a sex partner who has other sex partners.....
16							I do not use a condom during sex .....
17							I have not reduced my number of sex partners.....
18							I have missed appointments with my doctor.....
19							I do not seek ASO support for my HIV prevention.....
20							I share drug-injecting needles with my friends.....
21							I do what my traditional healer has suggested for my HIV prevention...
22							I discuss my HIV prevention strategies with my partner(s).....
23a							I have breastfed my baby despite HIV .....
23b							I have encouraged my wife/partner to breastfeed our baby despite HIV

## **APPENDIX J**

### **Questionnaire (Kiswahili)**

## SIFA ZA MAKUNDI YA WATU NA USULII WAO

1. Jinsia: \_\_\_\_\_ 1 Mwanamke \_\_\_\_\_ 2 Mwanamme

2. Una umri gani \_\_\_\_\_ (miaka)

3. Umezaliwa katika Wilaya ya Mkoa gani?

- \_\_\_\_\_ 1 Arusha
- \_\_\_\_\_ 2 Coastal
- \_\_\_\_\_ 3 Dar-es-Salaam
- \_\_\_\_\_ 4 Dodoma
- \_\_\_\_\_ 5 Iringa
- \_\_\_\_\_ 6 Kagera
- \_\_\_\_\_ 7 Kigoma
- \_\_\_\_\_ 8 Kilimanjaro
- \_\_\_\_\_ 9 Lindi
- \_\_\_\_\_ 10 Manyara
- \_\_\_\_\_ 11 Mara,
- \_\_\_\_\_ 12 Mbeya
- \_\_\_\_\_ 13 Morogoro
- \_\_\_\_\_ 14 Mtwara
- \_\_\_\_\_ 15 Mwanza
- \_\_\_\_\_ 16 Rukwa
- \_\_\_\_\_ 17 Ruvuma
- \_\_\_\_\_ 18 Singida
- \_\_\_\_\_ 19 Sinyanga
- \_\_\_\_\_ 20 Tabora
- \_\_\_\_\_ 21 Tanga
- \_\_\_\_\_ 22 Visiwa vya Zanzibari na Pemba
- \_\_\_\_\_ 23 Nje Tanzania (Wapi?) \_\_\_\_\_

4. Umelelewa katika dini gani?

- \_\_\_\_\_ 1 Kiislamu
- \_\_\_\_\_ 3 Katoliki
- \_\_\_\_\_ 4 Kilutheri
- \_\_\_\_\_ 5 Pentekoste
- \_\_\_\_\_ 6 Nyingine \_\_\_\_\_

5. Kwa sasa unafuata dini gani?

- \_\_\_\_\_ 1 Kiislamu
- \_\_\_\_\_ 3 Katoliki
- \_\_\_\_\_ 4 Kilutheri
- \_\_\_\_\_ 5 Pentekoste
- \_\_\_\_\_ 6 Nyingine \_\_\_\_\_

6. Kwa sasa dini unayofuata ina umuhimu kiasi gain kwako?

- ☐ 1 Si muhimu
- ☐ 2 Ni muhimu kiasi
- ☐ 3 Ni muhimu sana

7. Una kiwango gani cha elimu?

- ☐ 1 Sikusoma Kabisa
- ☐ 1 Shule ya Msingi (na chini ya hapo)
- ☐ 2 Sekondari (Kidato cha nne)
- ☐ 3 Ufundi
- ☐ 4 Sekondari (Kidato cha sita)
- ☐ 5 Diploma
- ☐ 6 Diploma ya juu
- ☐ 7 Stashahada ya Diploma
- ☐ 8 Shahada ya Kwanza
- ☐ 9 Uzamili
- ☐ 10 Uzamivu

8. Kwa sasa :

- ☐ 1 Umeajiriwa?
- ☐ 2 Umestaafu?
- ☐ 3 Hujaajiriwa?

8a. Endapo umeajiriwa:

Unafanya kazi masaa mangapi kwa wiki? \_\_\_\_\_.

9. Unajihusisha na ajira katika sekta zisizo rasmi? ☐ 1 Ndio. ☐ 0. Hapana.

10. Mapato yako ni kiasi gani?

\_\_\_\_\_. Kwa mwezi?

11. Kwa sasa:

- ☐ 1 Umeoa/Umeolewa?
- ☐ 2 Hujaoa/Hujaolewa?
- ☐ 3 Mmetengana?
- ☐ 4 Mmeachana (Taraka)?
- ☐ 5 Mjane?

11a. Kama Umeoa/Umeolewa:

Una/Uko katika ndoa za mitala? (mke zaidi ya mmoja)

☐ 1 Ndio. ☐ 0 Hapana.

11b. Kama ulikuwa umeoa/Umeolewa:

- Una/Uko katika ndoa za mitala? (mke zaidi ya mmoja)  
 \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.
- 11c. Kama Hujaaoa/Hujaolewa, Mmetengana, Mmeachana au Mjane:  
 Kwa sasa una mpenzi wa kudumu  
 \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.
12. Una mpenzi mwingine licha ya mke/mume/mpenzi wa kudumu?  
 \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.
13. Kutokana na ujuzi wako, mke/mume/mpenzi wa sasa nae ni mwathirika?  
 \_\_\_ 1 Ndio. \_\_\_ 0 Hapana. \_\_\_ 9 Sijui.
14. Una watoto? \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.
- 14a. Kama ni ndio:  
 Una watoto wangapi? \_\_\_\_\_
- 14b. Kama ni ndio:  
 Ni watoto wangapi ambao wana miaka chini ya 18 unaoishi nao sasa?
15. Je, unamiliki nyumba/chumba ambapo unaishi kwa sasa? \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.
- \_\_\_ 15 a. Kama hapana:  
 Je, umepanga nyumba/chumba ambapo unaishi kwa sasa?  
 \_\_\_ 1 Ndio. \_\_\_ 0 Hapana. \_\_\_ NA.
- \_\_\_ 15b. Kama hapana:  
 Je unaishi katika nyumba/chumba uliyo(cho)pewa na mtu unayemfahamu.  
 \_\_\_ 1 Ndio. \_\_\_ 0 Hapana. \_\_\_ NA.
- \_\_\_ 15c. Je, kama unaishi kwa mtu, una undugu gani na huyo mwenye nyumba? \_\_\_\_\_  
 1. Mzazi 2. Kaka 3. Dada 4. Ndugu. 5. Rafiki. 6. Mwajiri. 7. N.A.
16. Kwa ujumla una watu wangapi ambao unaishi nao? \_\_\_\_\_
- 16a. Ni watu wangapi unaoishi nao ambao ni watoto wa ndugu walio chini ya miaka 18? \_\_\_\_\_
17. Je, unamiliki nyumba sehemu nyingine? \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.
18. Unadhani ulipata virusi vya ukimwi lini? \_\_\_ Mwezi. \_\_\_ Mwaka.
19. Ni lini ulipima na kugundua kuwa una virusi vya ukimwi? \_\_\_ Mwezi. \_\_\_ Mwaka.
20. Je, una dalili zozote za Ukimwi? \_\_\_ 1 Ndio. \_\_\_ 0 Hapana.

20a. Kama ni Ndio:

Ni lini dalili zilianza kuonekana? \_\_\_\_ Mwezi. \_\_\_\_ Mwaka.

20b. Kama ni Ndio:

Ni dalili zipi kati ya hizi unazo mpaka sasa?

maumivu ya tumbo	____ 1 Ndio	____ 0 Hapana
magonjwa ya zinaa	____ 1 Ndio	____ 0 Hapana
maumivu yoyote wakati wa haja ndogo	____ 1 Ndio	____ 0 Hapana
kuvimba midomo/kuchubuka	____ 1 Ndio	____ 0 Hapana
kikohozi	____ 1 Ndio	____ 0 Hapana
homa ya uti wa mgongo	____ 1 Ndio	____ 0 Hapana
kuharisha	____ 1 Ndio	____ 0 Hapana
uchovu	____ 1 Ndio	____ 0 Hapana
homa	____ 1 Ndio	____ 0 Hapana
kupoteza hamu ya kula	____ 1 Ndio	____ 0 Hapana
kaposi's sarcoma (KS) (Sarakani)	____ 1 Ndio	____ 0 Hapana
malaria	____ 1 Ndio	____ 0 Hapana
majasho ya usiku	____ 1 Ndio	____ 0 Hapana
nimonia	____ 1 Ndio	____ 0 Hapana
vipele	____ 1 Ndio	____ 0 Hapana
kifua kikuu(TB)	____ 1 Ndio	____ 0 Hapana
kutapika	____ 1 Ndio	____ 0 Hapana
kupungua uzito	____ 1 Ndio	____ 0 Hapana

21. Je unatumia dawa za kupunguza makali/kurefusha maisha ? \_\_\_\_ 1 Ndio. \_\_\_\_ 0 Hapana.

21a. Kama Ndio:

Ulianza kutumia lini dawa hizo za kupunguza makali/kurefusha maisha? \_\_\_\_ Mwaka.

21b. Kama ni Ndio:

Je unajua aina zipi za dawa hizo unazozitumia? \_\_\_\_ 1 Ndio \_\_\_\_ 0 Hapana. \_\_\_\_ N.A.

21c. Kama Ndio:

Ni aina zipi kati ya hizi zifuatazo?

Duovir (Zidovudine (ATZ) 300mg) + Lamivudine 150 mg) + EFAVIR (Efavirenz 200mg)  
= USD 67.00 per month (pm) \_\_\_\_ 1 Ndio. \_\_\_\_ 0 Hapana.

DUOVIR + VIRAMUNE/NEVUMUNE (Nevirapine 200 mg)  
= USD72.00/42.00 pm \_\_\_\_ 1 Ndio. \_\_\_\_ 0 Hapana.

200 TRIOMUNE 40mg [Stavudine (d4T) 40 mg + Lamivudine (3TC) 150 mg + Nevirapine  
mg] = USD 33.00 \_\_\_\_ 1 Ndio. \_\_\_\_ 0 Hapana.

STAVIR 40mg (Stavudine 150mg) + LAMIVIR 150mg + EFAVIR 200mg



= USD 60.00 pm.     \_\_\_ 1 Ndio.     \_\_\_ 0 Hapana.

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Stavudine 40/30 + Didanosine 200 mg (ddi) + Efavir/Nevirapine  
USD 33.00 pm.     \_\_\_ 1 Ndio.     \_\_\_ 0 Hapana.

Duovir + Indnavir 400mg     USD72.00 pm \_\_\_ 1 Ndio.     \_\_\_ 0 Hapana.

Stavir 40mg Lamivir 150mg + Indivan pm. USD33 \_\_\_ 1 Ndio.     \_\_\_ 0 Hapana.

22. Je, unapata matibabu ya aina nyingine?     \_\_\_ 1 Ndio.     \_\_\_ 0 Hapana.

22a. Kama ni Ndio:     Ni yapi\_\_\_\_\_.

22b. Kama ni Ndio:

Ulianza lini?     \_\_\_\_\_ Mwaka.

23. Je, unatumia madawa ya kulevya?     \_\_\_ 1 Ndio.     \_\_\_ 0 Hapana.

23a. Kama ni Ndio:

Ni zipi? \_\_\_\_\_.

23b. Kama Ndio:

Je unatumia sindano za madawa ya kulevya? \_\_\_ 1 Ndio     \_\_\_ 0 Hapana.     \_\_\_ N.A.

23c. Kama Ndio:

Je, huwa unachangia na wenzako sindano za madawa ya kulevya? \_\_\_ 1 Ndio \_\_\_ 0 Hapana.

24. Umejiunga katika vikundi vingapi vya ASOs? \_\_\_\_\_

25. Kwa mara ya kwanza ulijiunga lini na ASO? \_\_\_\_\_

26. Kwa ujumla unaweza kusema hali yako ya afya ni:

- \_\_\_ 1 Mbaya
- \_\_\_ 2 Inaridhisha
- \_\_\_ 3 Ni Nzuri
- \_\_\_ 4 Ni Nzuri Sana

27. Kwa ujumla unaweza kusema hali yako ya maisha ni:

- \_\_\_ 1 Mbaya Sana
  - \_\_\_ 2 Mbaya
  - \_\_\_ 3 Inaridhisha
  - \_\_\_ 4 Ni Nzuri
  - \_\_\_ 5 Ni Nzuri Sana
-

28. Kabla hatujamaliza kuna jambo lolote ambalo ungependa kunieleza kuhusu uzoovu wako katika uzingatiaji wa kinga na tiba kwa wale wenye virusi vya ukimwi?

---

Ninakushukuru kwa kushiriki katika utafiti huu na kwa ushirikiano wako katika kukamilisha mahojiano yetu.

---

## MAENEO MBALIMBALI YA UCHUNGUZI WA AFYA KIDARAJIA

Inaaminika kuwa kila kipengele hapo chini kina uhusiano na hali yako ya afya kuhusu virusi vya ukimwi. Kwa kila kipengele ningependa unieleze endapo unakubaliana nacho au unakataa. Kipimo hiki ni kwa jinsi unavyoamini, ni dhahiri kuwa hakuna jibu sahihi na ambalo siyo sahihi. [Maelezo kwa mhoji. Msomee mhojiwa sentensi. Kisha, muulize kama anakubali au hakubali. Halafu, muulize, “Endapo anakubali kabisa (au hakubali kabisa), anakubali kiasi (hakubali) anakubali kidogo, (au hakubali”.]

1=SIKUBALI—KABISA--SB

2=SIKUBALI—KIASI--SA

3=SIKUBALI – KIDOGO--SD

4=NAKUBALI—KIDOGO--ND

5=NAKUBALI—KIASI--NA

6= NAKUBALI – KABISA--NB

		<b>S B</b>	<b>SA</b>	<b>S D</b>	<b>N D</b>	<b>NA</b>	<b>NB</b>
1	Kama afya yangu ikiwa mbaya, ni mwenendo wangu ndio utakaoamua kuwa ni lini nitakuwa na afya nzuri	1	2	3	4	5	6
2	Kwa hali yangu lolote litakalotokea ni sawa	1	2	3	4	5	6
3	Endapo nitamwona daktari wangu mara kwa mara nitapata nafuu kiafya.	1	2	3	4	5	6
4	Mambo mengi yanayoniathiri yanatokea mara chache.	1	2	3	4	5	6
5	Kila mara hali yangu inapokuwa mbaya, ni lazima nimwone daktari anayehusika.	1	2	3	4	5	6
6	Ninahusika moja kwa moja na hali yangu kuwa nzuri au mbaya.	1	2	3	4	5	6
7	Watu wengine wanachangia kwa kiasi kikubwa hali yangu kuwa nzuri, kuwa katika hali ya kawaida au kuwa mbaya.	1	2	3	4	5	6
8	Kwa kila jambo baya litakalotokea kuhusu hali yangu ni kutokana na makosa yangu.	1	2	3	4	5	6
9	Bahati tu inachangia kiasi kikubwa katika afya yangu kuwa ya kuridhisha.	1	2	3	4	5	6
1	Ili hali yangu iwe nzuri, watu wengine wana jukumu la kuhakikisha	1	2	3	4	5	6
0	kuwa ninatendewa mambo mazuri.						
1	Maendeleo ya afya yangu kwa kiasi kikubwa yanategemea bahati.	1	2	3	4	5	6
1							
1	Kitu kikubwa kiathiricho afya yangu ni kile nikifanyacho mwenyewe.	1	2	3	4	5	6
2							
1	Ninastahili pongezi pale ambapo afya yangu inaporidhisha na lawama	1	2	3	4	5	6
3	pale inapokuwa mbaya						
1	Kufuata maelekezo ya daktari ni njia nzuri ya kulinda afya yangu isiwe	1	2	3	4	5	6
4	mbaya zaidi						
1	Endapo afya yangu itakuwa mbaya ni majaliwa.	1	2	3	4	5	6
5							
1	Endapo nina bahati afya yangu itakuwa nzuri.	1	2	3	4	5	6
6							
1	Endapo afya yangu itabadilika na kuwa mbaya ni kwa sababu sijitunzi	1	2	3	4	5	6
7	vizuri.						
1	Aina ya msaada ninaopokea kutoka kwa watu wengine utaamua ni	1	2	3	4	5	6
8	mapema kiasi gani hali yangu ya afya itakuwa nzuri.						

## Hali ya Tatizo la Virusi vya Ukimwi Kidarajia

Nitakusomea vipengele mbalimbali vinavyoeleza jinsi ambavyo huenda umekuwa ukijisikia tangu ulipopata majibu ya kuwa una virusi vya ukimwi. Kwa kila kipengele, tafadhali nieleze endapo tangu ulipogundua kuwa una virusi vya ukimwi, unajisikiaje; kamwe, mara chache, wakati mwingine, aghalabu, au daima. Endapo kipengele hakikuhusu tafadhali nifahamishe.

Kamwe	Mara Chache	Wakati Mwingine	Aghalabu	Daima	NA
1	2	3	4	5	8

1	Kukubali hali yangu ya kuwa na virusi vya ukimwi imekuwa ngumu sana	1	2	3	4	5	8
2	Ninawasiwasi jinsi ya kuzuia virusi visiendelee na kuwa ukimwi	1	2	3	4	5	8
3	Nimegundua kuwa kuishi na virusi vya ukimwi ni jambo gumu	1	2	3	4	5	8
4	Sina tena malengo makubwa kwa maisha yangu ya baadaye	1	2	3	4	5	8
5	Kutokana na hali yangu ya kuwa na virusi vya ukimwi imekuwa vigumu kuwa na marafiki wa karibu	1	2	3	4	5	8
6	Sipati tena raha ya kufanya mapenzi	1	2	3	4	5	8
7	Ndoa yangu imekuwa katika matatizo kutokana na kuwa na virusi vya ukimwi	1	2	3	4	5	8
8	Ninaudhika ninapofikiria kuwa watu wanamsema mpenzi wangu/ wanawasema wapenzi wangu	1	2	3	4	5	8
9	Nina matatizo ya kuwashawishi watoto wangu wakubali hali yangu ya kuwa na virusi vya ukimwi	1	2	3	4	5	8
10	Nina wasiwasi kuwa sina tena muda mrefu wa kuishi	1	2	3	4	5	8
11	Ninajuta kumwambia mpenzi wangu kuhusu hali yangu ya kuwa na virusi	1	2	3	4	5	8
12	Kutokana na hali yangu ya kuwa na virusi, nimekuwa ninasumbuliwa kwa jinsi ninavyoonekana	1	2	3	4	5	8
13	Ninasikitika kutokana na hali yangu ya kuwa na virusi kujulikana kwa majirani zangu	1	2	3	4	5	8
14	Nina wasiwasi kuhusu yale yatakayoipata familia yangu nitakapokufa	1	2	3	4	5	8
15	Ninasikitika kuwa siwezi tena kuisaidaia familia yangu kiasi cha kutosha	1	2	3	4	5	8
16	Ninaogopa kuwa watu wanajua hali yangu, kwa kuniangalia	1	2	3	4	5	8
17	Ninawasiwasi kwa kuwa sipati huduma zinazostahili	1	2	3	4	5	8
18	Ninawasiwasi kuhusu wakati nitakaposhidwa kujihudumia	1	2	3	4	5	8
19	Ninahisi kukata tamaa kabisa	1	2	3	4	5	8
20	Sidhani kama kuna umuhimu wa kuwa na mipango ya baadaye	1	2	3	4	5	8
21	Ninasikitika kwa kuwa siwezi tena kufanya kazi yangu vizuri kutokana na hali yangu ya kuishi na virusi	1	2	3	4	5	8
22	Sina fedha kwa ajili ya vitu ninavyohitaji ili afya yangu iwe nzuri	1	2	3	4	5	8
23	Ninaogopa nitakuwa mzigo kwa familia yangu	1	2	3	4	5	8
24	Ninaogopa jinsi dalili za ugonjwa wa ukimwi zilivyobadili afya yangu	1	2	3	4	5	8
25	Ninaona aibu wakati majirani zangu wanapozungumza kuhusu hali yangu ya kipindi cha nyuma	1	2	3	4	5	8
26	Ninasikitika kwa kuwa siwezi kufanya kazi tene kwa bidii kutokana na hali yangu ya kuwa na virusi vya ukimwi	1	2	3	4	5	8
27	Ninawasiwasi kwa sababau ninaweza kuwa na motto	1	2	3	4	5	8
28	Ninawasiwasi kwa kuwa siwezi kumvutia mpenzi ambaye hana virusi vya ukimwi	1	2	3	4	5	8
29	Ninasikitika kwa yale yote niliyoshidwa kufanya kutokana na kuwa na virusi vya ukimwi	1	2	3	4	5	8
30	Ninaogopa kufa kwa ukimwi	1	2	3	4	5	8

## Chanzo cha Msaada wa Kijamii Kidarajia

Nitakusomea orodha ya makundi ya watu. Tangu ulipogundulika kuwa una virusi vya ukimwi umepata msaada wa kisaikolojia kiasi gani kutoka kwa kila mmoja. Ninaposema msaada wa kisaikolojia ninamaana; kukubalika, ushauri, uhuru wa kuongea kwa uwazi kuhusu ukimwi, uwezo wa kuzungumza kuhusu tatizo hilo, uwezo wa kuwashirikisha wengine matatizo unayopata na mengine yanayofanana na hayo. Tafadhali niambie kiasi cha msaada wa kisaikolojia unachopata kutoka kwa kila kundi, kama ni: Hakuna Kabisa Kiasi Kidogo, Kiasi, Kiasi cha Kutosha, au Kiasi Kikubwa. Tafadhali nipe jibu kulingana na hali yako. Endapo kundi la watu fulani halikuhusu tafadhali nifahamishe.

Hakuna Kabisa	Kiasi Kidogo	Kiasi	Kiasi cha Kutosha	Kiasi Kikubwa	NA
1	2	3	4	5	8

### Mtu/Watu

### A. Msaada wa Kisaikolojia

Mwenzi/Mpenzi	1	2	3	4	5	8
Watoto	1	2	3	4	5	8
Mama	1	2	3	4	5	8
Baba	1	2	3	4	5	8
Kaka	1	2	3	4	5	8
Dada	1	2	3	4	5	8
Ndugu wa Baba.....	1	2	3	4	5	8
Ndugu wa Mama.....	1	2	3	4	5	8
Ndugu wa mume/mke	1	2	3	4	5	8
Vikundi vya ushirikiano/Ujirani mwema na Jumuiya	1	2	3	4	5	8
Mwajiri	1	2	3	4	5	8
Wafanyakazi wenzio	1	2	3	4	5	8
Waganga wa Jadi	1	2	3	4	5	8
Waombeaji	1	2	3	4	5	8
Wafanyakazi wa Afya	1	2	3	4	5	8
Timu ya ASO	1	2	3	4	5	8
Wanachama wa ASO	1	2	3	4	5	8
Marafiki	1	2	3	4	5	8

### Chanzo cha msaada wa Kijamii Kidarajia

Endelea kufikiria kuhusu makundi hayo ya watu. Kwa sasa ninapenda kujua ni jinsi gani misaada halisi inapatikana kwa kila mtu au kwa kila kundi. Ninaposema misaada halisi nina maana, misaada ya kifedha, usafiri, malazi, kuangalia watoto, kutunza nyumba, kufua, chakula, madawa, elimu ya watoto n.k. Tangu ulipogundua kuwa una virusi vya ukumwi, kiasi cha upatikanaji wa misaada kutoka kwa kila mtu kikoje? Hakuna Kabisa Kiasi Kidogo, Kiasi, Kiasi cha Kutosha au ni Kiasi Kikubwa. Tafadhali nipe jibu kulingana na hali yako. Na endapo kundi la watu fulani halikuhusu tafadhali nifahamishe

Hakuna Kabisa	Kiasi Kidogo	Kiasi	Kiasi cha Kutosha	Kiasi Kikubwa	NA
1	2	3	4	5	8

#### Mtu/Watu

#### B. Misaada Halisi

Mwenzi/Mpenzi	1	2	3	4	5	8
Watoto	1	2	3	4	5	8
Mama	1	2	3	4	5	8
Baba	1	2	3	4	5	8
Kaka	1	2	3	4	5	8
Dada	1	2	3	4	5	8
Ndugu wa Baba.....	1	2	3	4	5	8
Ndugu wa Mama.....	1	2	3	4	5	8
Ndugu wa mume/mke	1	2	3	4	5	8
Vikundi vya ushirikiano/Ujirani mwema na Jumuiya	1	2	3	4	5	8
Mwajiri	1	2	3	4	5	8
Wafanyakazi wenzio	1	2	3	4	5	8
Waganga wa Jadi	1	2	3	4	5	8
Waombeaji	1	2	3	4	5	8
Wafanyakazi wa Afya	1	2	3	4	5	8
Timu ya ASO	1	2	3	4	5	8
Wanachama wa ASO	1	2	3	4	5	8
Marafiki	1	2	3	4	5	8

### Chanzo cha Msaada wa Kijamii Kidarajia

Mwisho, ni kuhusu kiasi cha msaada wa kupata taarifa kutoka kwa kila mtu. Msaada wa taarifa ni pamoja na taarifa za kitaalamu, taarifa za tiba na kinga, taarifa zaidi kuhusu huduma ambazo huzijui na nyingine zinazoendana na hizo. Kwa kila mmoja tafadhali nieleze endapo msaada wa taarifa unazopata tangu ulipojua kuwa una virusi vya ukimwi ni: Hakuna Kabisa, Kiasi Kidogo, Kiasi, Kiasi cha Kutosha au ni Kiasi Kikubwa. Tafadhali nipe jibu kulingana na hali yako. Endapo kundi la watu fulani halikuhusu tafadhali nifahamishe.

Hakuna Kabisa	Kiasi Kidogo	Kiasi	Kiasi cha Kutosha	Kiasi Kikubwa	NA
1	2	3	4	5	8

#### Mtu/Watu

#### C. Msaada wa Taarifa

Mwenzi/Mpenzi	1	2	3	4	5	8
Watoto	1	2	3	4	5	8
Mama	1	2	3	4	5	8
Baba	1	2	3	4	5	8
Kaka	1	2	3	4	5	8
Dada	1	2	3	4	5	8
Ndugu wa Baba.....	1	2	3	4	5	8
Ndugu wa Mama.....	1	2	3	4	5	8
Ndugu wa mume/mke	1	2	3	4	5	8
Vikundi vya ushirikiano/Ujirani mwema na Jumuiya	1	2	3	4	5	8
Mwajiri	1	2	3	4	5	8
Wafanyakazi wenzio	1	2	3	4	5	8
Waganga wa Jadi	1	2	3	4	5	8
Waombeaji	1	2	3	4	5	8
Wafanyakazi wa Afya	1	2	3	4	5	8
Timu ya ASO	1	2	3	4	5	8
Wanachama wa ASO	1	2	3	4	5	8
Marafiki	1	2	3	4	5	8

### Uzingatiaji Kidarajia

Sasa nitakusomea mlolongo wa mambo yanayoweza kufanyika au kuwatokea watu waliogundua kwamba wanaishi na virusi vya ukimwi. Huenda baadhi ya mambo yanayotajwa hapa yanakuhusu. Tafadhali nieleze iwapo kuna mambo ambayo yanaakisi yale unayofanya kama ni: Kamwe, Mara Chache, Wakati Mwingine, Aghalabu, au Daima. Endapo kipengele hakikuhusu tafadhali nifahamishe.

Kamwe 1	Mara Chache 2	Wakati Mwingine 3	Aghalabu 4	Daima 5	NA 8		
1	Sipati chakula ambacho ni mlo kamili.....	1	2	3	4	5	8
2	Huwa nafanya mwombezi wangu anielezavyo kuhusu tiba za ukimwi...	1	2	3	4	5	8
3	Ninatumia muda wangu kutunza afya yangu.	1	2	3	4	5	8
4	Ninahakikisha ninapata yale ninayohitaji	1	2	3	4	5	8
5	Ninafuata maelekezo ya dawa kama ninavyoelekezwa	1	2	3	4	5	8
6	Situmii chakula chochote cha ziada kuimarisha kinga yangu ya mwili	1	2	3	4	5	8
7	Ninatumia kondomu kila ninapofanya mapenzi	1	2	3	4	5	8
8	Sifuati matibabu niliyopewa na mganga wangu wa jadi.....	1	2	3	4	5	8
9	Ninahudhuria kliniki ya ASO kwa ajili ya kupata tiba	1	2	3	4	5	8
10	Ninasahau kutumia dawa nisipokumbushwa	1	2	3	4	5	8
11	Nina ratiba maalum ya mazoezi.	1	2	3	4	5	8
12	Nina mpenzi zaidi ya mmoja	1	2	3	4	5	8
13	Ninafuata utaratibu wa tiba niliopewa na daktari wangu	1	2	3	4	5	8
14	Huwa sitafuti ushauri kwa matatizo yahasuyo ugonjwa wa ukimwi.	1	2	3	4	5	8
15	Nina mpenzi ambaye anawapenzi wengine	1	2	3	4	5	8
16	Situmii kondomu wakati wa kufanya mapenzi	1	2	3	4	5	8
17	Sijapunguza idadi ya wapenzi wangu	1	2	3	4	5	8
18	Nimeshidwa kukutana na daktari wangu	1	2	3	4	5	8
19	Sijatafuta msaada wa ASO kwa ajili ya kuzuia virusi vya ukimwi.	1	2	3	4	5	8
20	Huwa ninachangia na wenzangu sindano za kutulevya	1	2	3	4	5	8
21	Ninafanya yal ninayoshauriwa na mganga wangu wa jadi kuhusu kuzuia virusi vya ukimwi	1	2	3	4	5	8
22	Ninajadili mbinu za kuzuia ukimwi na mpenzi wangu	1	2	3	4	5	8
23a	Nimemnyonyesha mwanangu ingawa ninajua kuwa nina virusi vya ukimwi	1	2	3	4	5	8
23b	Nimemshauri mke/mpenzi wangu kumnyonyesha mtoto wetu ingawa ni mwathirika	1	2	3	4	5	8
24	Nimemshauri mke/mpenzi wangu kumnyonyesha mtoto wetu ingawa ni mwathirika	1	2	3	4	5	8



## APPENDIX K

### 30-item HSS scale Factor Analysis (Rotated matrix)

Items	Factor1	Factor2
Accepting my HIV status has been hard for me	.52	-
I worry about how to prevent HIV from developing into AIDS	-	.54
I find living positively with HIV/AIDS difficult to do	-	.54
I no longer have big plans for my future	.64	-
Due to my HIV status, it is hard to have intimate relationships	.54	-
I don't find sex pleasurable any more	-	-
My marriage has been in trouble because of my HIV status	-	-
It embarrasses me to think that people talk about my sex partner(s)	.45	-
I have had problems making my children accept my HIV status	-	-
I worry about not having enough time left before I die	.72	-
I regret having disclosed my HIV status to my spouse/partner	.60	-
Due to my HIV status, I have become embarrassed by how I look	.73	-
I regret that my HIV status is known to my neighbors	.74	-
I worry about what will happen to my family when I die	-	.70
I regret that I can no longer contribute much to my/ and my family's support	-	.78
I fear that people know my HIV status just by looking at me	.76	-
I worry about not being able to get the care that I need	-	-
I worry about the day when I am not able to care for myself	-	.74
I feel like giving up on life altogether	.79	-
I do not think it worthwhile to make plans for the future	.62	-
I regret that I can no longer do my job well because of my HIV status	.51	.46
I do not have money for all the things that I need to keep healthy	-	.58
I fear that I will become a burden on my family	-	.79
I worry about the way AIDS symptoms have changed my looks	.58	-
I feel ashamed when my neighbors talk about my past	.71	-
I regret that I can no longer work as much because of my HIV status	.50	-
I worry that I could have a child who is HIV+	.45	-
I worry about not being able to attract a partner who is not HIV+	.54	-
I regret all the things that I have had to give up doing because of HIV	-	.48
I worry about dying from AIDS	.50	-

## APPENDIX L

### HSS exploratory factor analysis (17 items loading on Factor 1)

Item	Factor 1 Loading
Accepting my HIV status has been hard for me	.53
I no longer have big plans for my future	.67
Due to my HIV status, it is hard to have intimate relationships	.54
It embarrasses me to think that people talk about my sex partner(s)	.43
I worry about not having enough time left before I die	.73
I regret having disclosed my HIV status to my spouse/partner	.55
Due to my HIV status, I have become embarrassed by how I look	.74
I regret that my HIV status is known to my neighbors	.72
I fear that people know my HIV status just by looking at me	.74
I feel like giving up on life altogether	.75
I do not think it worthwhile to make plans for the future	.64
I regret that I can no longer do my job well because of my HIV status	.58
I worry about the way AIDS symptoms have changed my looks	.63
I feel ashamed when my neighbors talk about my past	.66
I regret that I can no longer work as much because of my HIV status	.50
I worry about not being able to attract a partner who is not HIV+	.59
I worry about dying from AIDS	.51

## APPENDIX M

### MHLC scale four factor solution (*Rotated Matrix*)

Items	Factor 1	Factor 2	Factor 3	Factor 4
If my condition worsens, it is my own behavior which determines how soon I will feel better again	-	-	.56	-
As to my condition, what will be will be	.41	-	.45	-
If I see my doctor regularly, I am less likely to have problems with my condition	-	-	-	.77
Most things that affect my condition happen to me by chance	-	-	.49	-
Whenever my condition worsens, I should consult a medically trained professional	-	-	-	.75
I am directly responsible for my condition getting better or worse	-	-	.55	-
Other people play a big role in whether my condition improves, stays the same, or gets worse.	-	-	-	-
Whatever goes wrong with my condition is my own fault	-	.51	-	-
Luck plays a big part in determining how my condition improves	.80	-	-	-
In order for my condition to improve, it is up to other people to see that the right things happen	-	-	.56	-
Whatever improvement occurs with my condition is largely a matter of good fortune	.83	-	-	-
The main thing which affects my condition is what I myself do	-	.69	-	-
I deserve the credit when my condition improves and the blame when it gets worse	-	.67	-	-
Following doctor's orders to the letter is the best way to keep my condition from getting any worse	-	-	-	.60
If I am lucky, my condition will get better	.72	-	-	-
If my condition takes a turn for the worse, it is because I have not been taking proper care of myself	-	.63	-	-
The type of help I receive from other people determines how soon my condition improves.	.49	-	-	-

## APPENDIX N

### Chance HLC Factor Analysis (Pre-rotated matrix)

Items	Factor1	Factor2
As to my condition, what will be will be	.50	-
Most things that affect my condition happen to me by chance	-	.60
Luck plays a big part in determining how my condition improves	.83	-
Whatever improvement occurs with my condition is largely a matter of good fortune	.86	-
If my condition worsens, it's a matter of fate	-	.73
If I am lucky, my condition will get better	.77	-

## APPENDIX O

### Three dimensions of social support (Informal and Formal)

#### *Correlations among Dimensions of Informal and Formal Social Support*

	Informal Sources of Emotional Support (A)	Informal Sources of Practical Support (B)	Informal Sources of Informational Support (C)
Informal Sources of Emotional Support (A)	-	.76*	.71*
Informal Sources of Practical Support (B)		-	.75*
Informal Sources of Informational Support (C)			-
Formal Sources of Emotional Support (A)	-	.62*	.64*
Formal Sources of Practical (B)		-	.62*
Formal Sources of Informational Support (C)			-

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